

**The effect of coping strategy and locus of control on perception of pain and
perceived health in children with Juvenile Chronic Arthritis.**

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1998



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Acknowledgements

I would like to thank both my supervisors Carolyn Wesson and Leo Harding for their enthusiasm and support throughout this study. Their ideas, suggestions and guidance have been invaluable. I would also like to thank Brenda Renz for agreeing to be an independent source of information for the families. In addition, my thanks go to Dr Raashid Luqmani, Consultant Rheumatologist, for his support and input as well as the staff of the Rheumatology Clinic, Royal Hospital for Sick Children, Edinburgh. I would also like to thank Frank Charlton for his advice on design, when an initial idea was struggling into practice. In addition, my heartfelt thanks to Mick Power who has continued to offer the support of his expertise in the final stages of this write up. My thanks also to Julie Barlow and Karen Shaw of Coventry University, whose help and assurance that this study was of general interest to a wider audience, provided much needed encouragement. Most importantly I would like to thank the families and children who agreed to take part. Without their help there would have been no study. I hope that the findings herein, and in the future, can repay their generosity. Finally, I would like to thank my wife, Gill, whose limitless patience and comfort sustained me throughout, and my parents, who have supported me throughout my education.

Declaration

“This thesis has been composed by myself and the work contained herein is my own”

_____ Ion James Falconer Wyness

Abstract

Juvenile Chronic Arthritis is a chronic, persistent condition which affects approximately 1 in 1000 children in the United Kingdom (Ansell, 1996). Whilst the range of chronic illnesses is vast, it is generally assumed that all types carry a substantial risk for a child's physical and emotional growth and development (Pless & Pinkerton, 1975). Recent research has begun to report findings which contradict the notion that a child with a chronic condition is inevitably going to show maladaptive behaviour and functioning. A new approach (for example Bradford, 1997; Eiser, 1993) has begun to emphasise the role of children's coping and the concept of individual competence. Theories of chronic childhood illness proposed by, for example, Varni and Wallander (1988), emphasise the importance of integrating research with ideas from general developmental psychology. This shift in emphasis forms the basis of this research. The present study focuses on the experience of pain in children with Juvenile Chronic Arthritis. In particular, the study examines how children's coping strategies (Kidcope) and health beliefs (Children's Health Locus of Control Scale) affect their level of reported pain (Varni-Thomson Paediatric Pain Questionnaire), as well as their reported anxiety (Revised Childhood Manifest Anxiety Scale), self-esteem (Self Perception Profile for Children, modified by Hoare, Elton, Greer, & Kerley, 1993) and depression (Childhood Depression Inventory). Children between the ages of seven and 14 were recruited from the Paediatric Rheumatology Clinic at the Royal Hospital for Sick Children. Each child completed the above assessment measures whilst attending the interview. Results are discussed in relation to the planning of psychological interventions with children and families who are experiencing difficulties in coping with Juvenile Chronic Arthritis. In addition, methodological issues and implications for future research are presented.

1. Introduction

1.1 Chronic illness: An introduction

The purpose of this introduction is to provide the rationale which underpins the current research. Initially, it is important to provide an introduction to the extent and nature of chronic illness, before narrowing the focus to Juvenile Chronic Arthritis itself.

The study is primarily concerned with the contribution played by both coping strategies and health beliefs, in adaptation to the disease process of Juvenile Chronic Arthritis. Thus, the concepts of coping and health locus of control will also be discussed and their importance in the realm of chronic illness will be established. Finally, the basis of the present research will be summed up, providing the basis for statement of hypotheses.

Throughout this study the British term Juvenile Chronic Arthritis will be used in preference to the American label of Juvenile Rheumatoid Arthritis. However, it should be noted that these terms are often used interchangeably in the literature and refer to the same chronic childhood illness.

1.1.1 The extent of chronic illness

In examining the range of literature, one can synthesise a simple, general definition of chronic illness as an 'incurable illness of at least three months duration, which can last for an entire lifetime' (Eiser, 1990a, 1993; Midence, 1994). Wallander and Varni (1998) stated that for a condition to be considered truly 'chronic', it should (a) interfere with daily functioning for more than 3 months in any year, (b) result in hospital treatment of more than one month in a year, or (c) is thought at time of diagnosis to do either (a) or (b). Evidence suggests that 10% to 20% of children may suffer from a chronic illness in Western developed countries (Pless & Roghmann,

1971; Cadman, Boyle, Szatmari, & Offord, 1987; Gortmaker & Sappenfield, 1984; Hobbs, Perrin, & Ireys, 1985). It is also believed that 10% of the chronically ill population (or between 1 and 2% of the general population) have severe forms of chronic disorders (Gortmaker & Sappenfield, 1984).

Gortmaker (1985) reported that the most common chronic conditions found in children are asthma (10 per 1,000 live births) with a survival rate equivalent to the normal population, congenital heart disease (8 per 1,000) with 52% of sufferers reaching the age of 15, and chronic kidney disease (2 per 1,000), again with a life expectancy similar to healthy children. The number of children suffering from chronic arthritis is estimated as 1 in 1,000 live births (Hagglund, Schopp, Alberts, Cassidy, & Frank, 1995; Petty, 1982). Insulin dependent diabetes is estimated to affect 1.43 per 1,000 children (Calnan & Peckham, 1977).

Whilst the range of paediatric chronic conditions is broad, some authors have called for a 'non-categorical' approach to the study and conceptualisation due to the often observed overlap between conditions (Pless & Pinkerton, 1975). In their call for a broader approach, they note that the range of physical disorders may overlap in terms of the nature of onset, course, life threat potential, intrusiveness/ pain of treatment, secondary functional and cognitive disabilities, as well as the visible/ social stigma and the fact that much of the burden of care rests with families (Pless & Pinkerton, 1975; Stein & Jessop, 1982; 1984; Rolland, 1987; 1994).

Decades of improvements in hygiene have greatly reduced the life threat of many childhood diseases. In addition, modern medicine has advanced to effectively control many aspects of disease, such as the pain and intensity of symptoms, as well as reduce the threat to life in a number of previously fatal conditions. For example the discovery of insulin in the 1920's has greatly improved the long-term prognosis for diabetics, generally to the longevity one would expect of a healthy population. The use of antibiotics for conditions such as cystic fibrosis, has meant a significant improvement in the life expectancy of children who suffer from these conditions.

Despite this, *chronic* childhood illnesses, such as those listed above, *cannot be cured*. In this way, children who suffer from these afflictions are often faced with a life-time of hospital appointments and admissions, diagnostic procedures, and painful, intrusive treatments (Eiser, 1993). The management and treatment of children with chronic disease has now become the long-term focus of the majority of paediatric services. The aim of medical treatment has now become to promote independence, to enable the child to undertake as much of the responsibility for management as possible, and reduce the potential negative aspects of the disease process, thus allowing the child to lead as 'normal' a life as possible (Eiser, 1990b).

1.1.2 Consequences for the child and family

With the move to managing illness in the community, the burden of caring for a child with a chronic illness has increasingly been shifted to the parents. This inevitably results in both physical and emotional demands on the parents (Eiser, 1990b).

In purely physical terms, parents are now responsible for undertaking the day to day care of their child, such as administering medication, overseeing restrictive diets, as well as the general monitoring of disease activity. In addition, parents must learn specific tasks, such as giving physiotherapy and monitoring blood glucose levels.

In addition to these practical tasks of the management of the child's illness, the family need to cope with the emotional effects of living a child or sibling who has a chronic illness. These burdens can take many forms, from the reappraisal and altering of aspirations for the child's future to coping with relapse following periods of stability. The uncertainty for the child's future physical and psychological health can be the most difficult aspects with which parents must cope (Eiser, 1987).

Eiser (1990a) in her review of the psychological effects of chronic disease, outlines the areas in which chronic disease can affect the child and family. Firstly, the effects

on the child can manifest themselves in terms of increased vulnerability, resulting in the potential for problems of emotional and behavioural development. The focus on negative aspects of this effect and recent dissatisfaction with this viewpoint are detailed below.

Secondly, the effects on the family are often assessed in terms of the family's "adjustment". Researchers have tended to concentrate on the view that chronic disease leads to an increased incidence of marital disruption, divorce, stress, and psychopathology in parents and siblings. Unfortunately, there has been little emphasis on coping resources within the family, as well as the role played by the father (Eiser, 1990a).

Thirdly, and in addition to the marital disruptions acknowledged above, research has indicated that siblings may be adversely affected in terms of lower self-concepts, social isolation, or resentment of the parents' involvement with the chronically ill child (for a review, see Eiser, 1990b).

1.1.3 The task facing paediatric psychology

Set against the background of constant medical advances and following the enormous development of the role of psychology within general medical settings, the constantly developing role of the paediatric psychologist is the treatment of medically ill and injured children (Peterson and Harbleck, 1988).

However, when considering the spectrum of difficulties which present to clinicians in this client group, it is not surprising that the potential area is extremely broad (Drotar, Johnson, Iannotti, Krasnegor, Mathews, Melamed, Millstein, Peterson, Popiel, & Routh, 1989). Paediatric psychologists have been involved in areas from the development of skills necessary to treat physical disease, to the use of intervention designed to reduce children's acute and chronic pain, as well as long-term prevention of medical disorders and trauma (Peterson, Sherman, and Zink, 1994).

Peterson and colleagues (1994) write that it is essential for the paediatric psychologist to “.... consider the differences in approaches dictated by the age, life experiences and the cognitive, affective, and social maturity of the child.” (page 360).

Unlike interventions with other client groups, such as adults, working with children must always be evaluated in relation to a rapidly altering background of child growth and development. Karoly (1982) also suggests, that when working with acute and chronically ill children, an extensive knowledge of normal development is not necessarily completely adequate. Chronic disease can alter the rate at which a child attains many developmental skills (Karoly, 1982), whilst acute illnesses may lead to temporary losses in previously attained skills (Willis, Elliott & Jay, 1982), and a reduction in the desire or ability to acquire new skills (Magrab & Calcagno, 1978). In addition, Soni and colleagues report that some medical treatments may cause permanent decreases in areas such as cognitive ability (Soni, Morten, Pitner, Owens, & Powazek, 1975).

Thus, when helping children and their families cope with chronic childhood illness, the clinical psychologist faces a complex task. Peterson and colleagues (1994) summed up this task as:-

“..... recognising the complex interweavings of prior developmental competencies and current abilities on the one hand, with each medical disorder and its treatment on the other, is the crucial and formidable assignment accepted by those who practice paediatric psychology.”
(page 360)

One key area involves the facilitation of adjustment to chronic illness. Firstly, this can involve teaching specific skills such as increasing age appropriate behaviours (Manella and Varni, 1981), and teaching medical treatment skills to children (Gilbert, Johnson, Spillar, McCallum, Silverstein, & Rosenbloom, 1982) and parents (Sergis-Deavenport and Varni, 1983).

Secondly, psychologists intervene to enhance medical compliance, such as reinforcing dietary compliance (Carney, Schechter, & Davis, 1983), reinforcing difficult or painful aspects of medical regimes (Rapoff, Lindsley, & Christopherson, 1984), and teaching problem solving skills to parents (Graves, Meyers & Clark 1988).

Thirdly, psychologists help alleviate symptoms including chronic headache (Hoelscher & Lichstein, 1984), muscle and joint pain (McGrath, 1990), recurrent non-specific abdominal pain (Sanders, Rebgetz, Morrison, Bor, Gordon, Dadds, & Sheppero, 1989) and seizure activity (Ince, 1976).

Another key area involves interventions to reduce distress during common medical procedures. This can encompass a wide variety of medical interventions such as venipunctures and injections (Manne, Redd, Jacobsen, Gorfinkle, Schorr, & Rapkin, 1990), diagnostic oncology procedures (Jay, Elliott, Ozolina, & Olson, 1983) and burn hydrotherapy (Elliott & Olson, 1983).

Finally, it is worth noting that paediatric psychologists are not only involved in interventions that are concerned with the rigors of acute and chronic illness. The scope of work also involves psychologists in health promotion interventions. These activities can include encouraging daily health habits such as dental hygiene (Lund & Kegeles, 1982), dietary habits (Perry, Murray & Klepp, 1987) and activity levels (Danforth, Allen, Fitterling, Danforth, Brown, & Drabman, 1990). In addition work of paediatric psychologists has included programmes to avoid substance abuse (Johnson, Hansen, Collins, & Graham, 1985) and injury prevention (Roberts & Turner, 1986).

When one considers the wide variety of interventions in which paediatric clinical psychologists are involved, and the above description is by no means an exhaustive list, it becomes apparent that the implications of childhood chronic illness are vast. As Eiser (1993) points out, these children face a lifetime of complications associated with the course of their disease, as well as the normal, considerable task of developing cognitive and behavioural skills alongside their healthy peers. It is not surprising that considerable effort has been placed into the study of the vulnerability of these children to the effects of chronic illness. The next section will present some of this literature, followed by a re-examination of the rationale which assumed that childhood chronic illness is inevitably associated with psychopathology.

1.1.4 The effects of chronic illness

Whilst the range of chronic illnesses is vast, it is generally assumed that all types carry a substantial risk for a child's physical and emotional growth and development (Pless & Pinkerton, 1975). There is an extensive literature which lays out the various theoretical foundations which believe chronic conditions inevitably lead to negative psychosocial consequences for the child. Adler (1917) first postulated the 'perceived inferiority' of children with a chronic illness. Negative consequences of altered 'body image' have been proposed by Schilder (1950) and Barker and colleagues (Barker, Wright, Myerson, & Gonick, 1953). In addition, Wright (1964) wrote about the roles of mourning and devaluation in response to illness and disability.

Research has indicated that children with a chronic illness are more likely to exhibit signs of psychological and social maladjustment than healthy peers, as measured by variables such as school attendance, cognitive achievements and behavioural reports (Schiffer & Hunt, 1963; Pless, 1984; Orr, Weller, Satterwhite, & Pless, 1984).

A study by Cadman and colleagues (1987) demonstrated that children with a chronic disease and a physical disability ran a three times greater risk of psychiatric disorder

than their healthy peers and were at a 'considerable' risk of emotional maladjustment. Mrazek, Anderson & Strunk (1985) reported that 35% of a group of asthmatics displayed emotional disturbance, compared to none of the control group. In addition they were more likely to be depressed. Other studies have identified the risk of maladjustment, and behavioural and emotional disturbance with specific disease groups. These are reported below:-

- cancer (Taylor, Albo Phebus, Sachs, & Bierl, 1987; Mulhern Ochs, & Fairclough, 1987; Wasserman, Thomson & Willams, 1987; Worchel, Nolan, Willson, Purser, Copeland, Pfefferbaum, 1988),
- diabetes (Johnson, 1988; Fonagny, Moran, Lindsay, Kurtz, & Brown, 1987; Close, Davies, Price, & Goodyer, 1986)
- sickle-cell anaemia (Hurtig & White, 1986; Hurtig, Koepke, & Park, 1989)
- renal disease (Beck, Nethercut, Crittenden, & Hewins, 1986; Garralda, Jameson, Reynolds, & Postlethwaite, 1988).

1.1.5 Criticism of the traditional approach

However, this 'traditional' view of childhood chronic illness, one which emphasises the high risk for behavioural, emotional, and developmental disturbance in these children, has been re-examined and criticised by recent authors. Criticism has focused on methodological problems in the traditional research, as well as the tendency for studies to concentrate on maladjustment to the detriment of identifying resilience factors and coping resources.

Many of the studies carried out have been heavily criticised on methodological grounds (Pless, Cripps, Davies, & Wadsworth, 1989; Lemanek, Moore, Gresham, Williamson, & Kelley, 1986). Specifically, criticism has been levelled at poor sample sizes, biased samples with too much selection of ill children, limited use of control groups, as well as reliance on cross-sectional designs.

Recently authors (for example Eiser, 1990b, 1993; Bradford, 1997; Midence, 1994) have begun to develop ideas which had been discussed earlier. Specifically, the fact that many children in highly aversive situations are capable of showing remarkable resilience (Murphy, 1974; Anthony, 1974). The traditional or 'deficit-centred' (Eiser, 1990b) approach has concentrated on identifying psychopathology or dysfunction in children and families. Midence (1994) summed up his criticism of this approach as follows "Past research has focused on the negative aspects of disease to such an extent that the resilience shown by many children and their families has not been recognised." (Page 313). As Olson, Johansen, Powers, Pope, & Klein (1993) point out, this tendency of studies to emphasize the negative outcomes associated with childhood chronic disease has only relatively recently begun to change (Perrin & MacLean, 1988; Perrin, Ramsey, & Sandler, 1987)

There is a paucity of information and research attempting to understand the coping strategies used by children, and the associated factors which contribute to successful coping. Drotar (1981) stated that the ability to effectively employ coping strategies, may go some way to explaining the level of a child's psychological functioning. In addition, there appears to be little understanding of how children's perceptions affect their experience of paediatric chronic illnesses (Midence, 1994).

1.1.6 An alternative, positive approach to chronic illness

In redefining the approach to the study of children with a chronic illness, a new approach has begun to emphasise the role of children's coping and the concept of individual competence. In addition, Eiser (1990b) highlights the importance of utilising models drawn from mainstream psychology which has shifted the focus of research. She writes "..... families and children with chronic disease are not seen as deviant, but as ordinary people in exceptional circumstances." (P 85).

Recent research has begun to report findings which contradict the notion that a child with a chronic condition is inevitably going to show maladaptive behaviour and

functioning. Zeltzer and colleagues (Zeltzer, Kellerman, Ellerberg, Dash, & Rigler, 1980) found that a group of adolescents with renal disease experienced less disruption of everyday life than a group of healthy peers. Children with mild forms of illness may show poorer coping strategies (Markova, 1979; Perrin, MacLean, & Perrin, 1989) and more adjustment difficulties (Drota & Bush, 1985) than other children with more severe, even life-threatening forms of disease. In a longitudinal study of a sample of births in England, Wales, and Scotland Pless and colleagues (Pless, Cripps, Davies, & Wadsworth, 1989) reported that children diagnosed with a chronic condition had a very good long-term psychosocial prognosis. For instance, they were just as likely to get married and become parents as their healthy peers. Additional studies have reported evidence to contradict the notion that chronic illness inevitably leads to negative consequences in children with asthma (Kashani, Koenig, Shepperd, Wilfley, & Morris, 1988), cancer (Malpas, 1988), and sickle-cell anaemia (Lemanek and colleagues 1986).

In his review article Midence (1994) concluded:-

“The available evidence suggests that most children with chronic illness do not manifest psychological disturbance..... the vast majority of these children do not demonstrate psychological maladjustment and seem to cope very well with their illness.” (p 321).

The problem facing much of the research concerning the adaptation of children to paediatric chronic illness, is the lack of coherent definitions of adaptation and coping (Midence, 1994). Despite this, the concept of coping has now started to become recognised as a central feature in the study of why children's response to illness and stress can be so variable and why outcomes differ (Newman, 1990).

1.2 The concept of coping

1.2.1 Coping and illness

The traditional view that chronic illness has a negative effect on the child and family has primarily focused interest on the child who is not functioning adequately. As a consequence, little is known about the coping skills of the large numbers of children who effectively adapt to and cope with their illness (Eiser, 1990b). Lazarus and Folkman (1984) have defined coping as “the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person” (p 283). Their definition appears to compliment the theory of chronic illness proposed by Varni and Wallander (1988), which is described in detail below. This shift in theory emphasises the importance of integrating research with ideas from general developmental psychology.

Coping strategies refer to the process of adaptation to stress, including both positive and negative responses (Olson et al, 1993). In Lazarus and Folkman’s (1980, 1984) model of coping, the first stage in this process involves cognitive appraisal of the situation, following which an individual can regulate feelings (‘emotion focused’ coping) or attempt to manage the problem (‘problem focused’ coping). Studies have found that problem solving was associated with fewer symptoms (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986), and superior outcome, compared with the use of confrontive coping and distancing (Folkman, Lazarus, Gruen, & DeLongis, 1986). In addition, problem solving resulted in more positive and less negative emotion (Folkman & Lazarus, 1988). The effectiveness of cognitive coping strategies in adults has been noted in studies of migraine (Brown, 1984), during dental treatment (Chaves & Brown, 1987), and in rheumatoid arthritis sufferers (Brown and Nicassio, 1987).

However, the effectiveness of cognitive appraisal in children has received little attention (Olson et al, 1993), despite the key emphasis placed on the central mediating

role of cognitive processes within many models of coping (for example Folkman & Lazarus, 1980; Silver & Wortman, 1980; Weisz, Rothbaum, & Blackburn, 1984a, 1984b). A study by Beckham and colleagues found that, contrary to previous assertions that demographic variables and medical status variables are most important in examining rheumatoid pain (for example Anderson, Bradley, Young, McDaniel, & Wise, 1985), patients' own coping efforts explained the majority of variance in measures of pain, physical disability, psychological disability, depression, and severity of daily hassles in rheumatoid arthritis (Beckham, Keefe, Caldwell, & Roodman, 1991).

Varni and Wallander (1988) believe that the factors associated with adjustment to chronic illness are dependent on intrapersonal, interpersonal as well as social-ecological domains. They emphasise the importance of individual and family coping strategies and skills, rather than the traditional focus on maladjustment and deviance. Possibly the most important consequence of such a shift, is the implications for the development of intervention programmes (Fehrenbach & Peterson, 1989). Similarly Midence and colleagues (Midence, Fuggle, & Davies, 1993) suggest that a child's response to his/her illness depends on a) characteristics of the illness, b) characteristics of the child, c) characteristics of the family and social environment, and d) the provision of effective social, medical and environmental support.

Lazarus (1993), in a review of theory on coping, called for researchers to concentrate on the nature of coping strategies in specific situations. This reflects other theoretical viewpoints, which focus on competence and coping in specific situations (Hops, 1983), and fits well with the increasing belief that children and families with chronic conditions are in fact ordinary people dealing with specific difficulties (Eiser, 1990b). Murphy (1962) viewed coping as an adaptive process for dealing with challenges from the environment. In this way, coping is used in situations in which reflexes are unable to manage outcomes. Mastery is achieved when coping strategies become well practised.

1.2.2 Coping with a chronic illness

Children with a chronic illness are expected to deal with the range of developmental tasks that face every child and adolescent. However their ability to develop and cope with the normal range of stressors may be affected by the additional problems associated with their chronic illness (Midence, 1994; Olson and colleagues 1993). The ability to employ coping strategies is not only critical for achieving control over illness, it is also vital for short-term and long-term adaptation to chronic illness (Band, 1990; Ellerton, Ritchie, & Caty, 1994). This last point is crucial in the study of children adapting to chronic illness. Researchers have found that the patterns of coping used by adults, are often extensions of those developed as children (Garmezy & Rutter, 1983). Thus, children's coping has important implications for long-term adjustment.

Wallander and colleagues (Wallander, Varni, Babani, & Banis, 1989) proposed the risk and resistance model of childhood chronic illness. They hypothesised that 'risk' factors included factors such as disease status, functional dependence, and psychosocial stress. By contrast, stress processing and coping, as well as social ecological factors were identified as 'resistance' determinants associated with improved adaptation. This model has formed the basis of much research into childhood chronic illness.

The risk and resistance model of Wallander and colleagues (which is described in more detail below) is directly comparable with other frameworks attempting to explain the adaptation to chronic illness; for example the gate control theory (Melzack & Wall, 1983) and social ecological models of pain (Ross & Ross, 1988). Both the latter theories emphasise the important roles of social, motivational-affective and cognitive-evaluative factors in the pain experience of people with rheumatic diseases. The assumption of all three models is that disease characteristics alone cannot explain reported pain. In this way, it is hypothesised that psychological factors exert a significant influence on pain and disease adaptation.

1.2.3 An integrated view of children's coping

In a review of the theoretical models which have been applied to children's coping, Compas and colleagues re-asserted the view that coping strategies can have either risk or protective effects on the experience of paediatric chronic conditions, and thus predict both the short and long term outcomes for these children (Compas, Worsham, & Ey, 1992).

Compas identified a number of conceptual models which have been applied to the coping efforts of children in relation to stressful situations (Compas, 1987). Specifically, he identified the cognitive appraisal model (Lazarus & Folkman, 1984), the two-dimensional model of primary and secondary control (Rothbaum, Weisz, & Snyder, 1982; Weisz, Rothbaum, & Blackburn, 1984), the ego-psychological model (Murphy & Moriarty, 1976) and the monitoring versus blunting model (Miller, 1980).

Compas and colleagues (1992) reported that the above distinct conceptual models, were all essentially emphasising the same basic distinction in coping. This distinction centres around the intention or function of coping efforts. The authors formalised this distinction into 'Type I' and 'Type II' coping strategies.

Type I coping refers to strategies designed to change or master particular, perceived stressful, characteristics of the person or environment, or the relationship between these two elements. The various labels given to this subtype of coping in the literature are 'problem focused coping' (Lazarus and Folkman, 1984), 'primary control coping' (Band & Weisz, 1988), 'Coping I' (Murphy & Moriarty, 1976), and 'monitoring' (Miller, 1980). Additional labels included in the Type I coping include 'approach coping' (Altshuler & Ruble, 1989), 'problem solving' (Wertleib, Weigel, & Feldstein, 1987), as well as 'active coping' (Peterson, 1989).

Type II coping describes children's efforts to manage or regulate the negative emotions which are generated as a consequence of the stressful episode. This style of coping is referred to as 'emotion focused coping' (Lazarus and Folkman, 1984), 'secondary control coping' (Band & Weisz, 1988), 'Coping II' (Murphy & Moriarty, 1976), and 'blunting' (Miller, 1980), as well as 'emotional manipulation', 'tension reduction', 'avoidance' (Altshuler & Ruble, 1989), 'emotional management' (Wertleib, Weigel, & Feldstein, 1987), and 'avoidance' (Peterson, 1989).

1.2.4 Coping research

The importance of coping as a mediating factor for children with a chronic illness has only recently become an area for researchers. In examining children's response to stressful healthcare procedures, Ellerton and colleagues concluded that information seeking (an active strategy) appeared to be an important mediating factor (Ellerton et al, 1994). In a review on children's coping with stressful medical procedures, Peterson (1989) concluded that, in general, 'active' or 'problem focused' coping was associated with better psychosocial functioning in terms of behaviour, emotional status and somatic symptom manifestation. However, Midence (1994) points out that, whilst studies have looked at coping skills in children with diabetes (for example, Kovaks, Feinberg, Paulauskas, Finkelstein, Pollock, & Crouse-Novak, 1985) and leukaemia (Kupst & Schulman, 1988), little is known about other chronic conditions. Indeed, it is unlikely that the skills identified for diabetes, will necessarily be applicable to Juvenile Chronic Arthritis, for example.

The research which has been attempted on cognitive coping strategies has revealed promising results. Higher frequency of problem solving in children appears to be associated with a reduction in adjustment problems (Compas, Malcarne, & Fondacaro, 1988). Furthermore, the use of emotion focused coping strategies, in other words those designed to regulate the emotional response to a stressor, has been linked with higher levels of anxiety (Brown, O'Keefe, & Sanders, 1986). Additional research with diabetic children has indicated that the general coping strategies they

employ are similar to controls (Spirito, Stark, & Williams, 1988) and that problem focused strategies are associated with better control over their illness (Delameter, Kurtz, & Bubb, 1987), as well as fewer behavioural problems (Band, 1990; Band & Weisz, 1990).

The study by Olson and colleagues (1993) examined the coping strategies of children with asthma, diabetes, and juvenile rheumatoid arthritis. They reported that children suffering from these chronic conditions spontaneously use cognitive coping strategies in the same way as their healthy peers. Interestingly, they found variations in the coping strategies used depending on the type of event. The study concluded that “Children with chronic illnesses may learn cognitive strategies for the familiar painful events in situations specific to their care, but may not readily transfer this coping skill to other painful procedures.” (p. 221). This fits neatly with the theoretical standpoint of Lazarus (1993) described above, who advocated the study of coping strategies in specific situations, as well as results of research with healthy adults (Lazarus and Folkman, 1984).

1.2.5 Assessment of children’s coping

Eiser (1993), reported that the major difficulty in the assessment of children’s coping strategies lay in the multiple ways of categorising coping which have been used by research. In the adult literature substantial research has been undertaken and the focus has been on the use of standardised assessment measures. For example, 13 different conceptual strategies have been identified (Carver, Scheier & Weintrub, 1989) using the Pain Coping Strategies Questionnaire (Rosenstiel and Keefe, 1983). However, there has been little effort to use standardised assessment procedures for children’s coping strategies.

Eiser (1993) felt that the development of scales, such as the KIDCOPE, would help address this disparity between the adult and child research methodology. The KIDCOPE (Spirito, Stark & Williams, 1988; Spirito, Stark & Tyc, 1989) attempts to

assess the different aspects of coping in children. The scale, adapted for 7-12 year olds and 13-18 year olds, survey the implementation and perceived effectiveness of 10 commonly used cognitive and behavioural strategies. It is hoped that the development of such measures will help address the paucity of coping measures available for research and thus enable salient comparisons to be made across studies.

Based on the development study, Spirito and colleagues (Spirito, Stark & Tyc, 1989) reported that females generally employed a broader repertoire of coping strategies and were more likely to use emotion focused strategies. In a study of chronically ill children, Spirito et al (1988) found that when children referred for emotional help were compared with their non-referred peers, it was found that they were more likely to use the passive strategies of distraction, social withdrawal and wishful thinking. On the basis of these findings, it was suggested that clinical interventions should aim to encourage children to utilise problem focused (for example, problem solving), rather than emotion focused coping strategies.

In a further study using the KIDCOPE, Stark, Spirito & Tyc, (1991) found that over 50% of their paediatric hospital sample reported other factors which were associated with the hospital stay itself (e.g. lack of privacy, poor food), as their primary concerns. Based on the results of their study, the authors argue that focus of research should shift beyond analysis of strategies attempting to cope with pain.

A further concern raised by authors discussing the assessment of children's coping with chronic illness, is the use of assessment measures which may reflect the nature and course of the disease itself rather than underlying pathology. A study by Daltroy and colleagues (Daltroy, Larson, Eaton, Partridge, Pless, Rogers, & Liang, 1992) which examined the psychosocial adjustment of children with chronic arthritis, concluded that there was a modest increase in behavioural problems of a sample of 102 children.

However, the use of the referenced norms for the Childhood Behaviour Checklist (CBCL) was cautioned by the authors, as they felt the scores may have been inflated by questions which reflect the disease process itself. The CBCL is a parent report based measure and it has been suggested in clinical experience that parents may underestimate their child's abilities and thus restrict their activities (Daltroy et al, 1992). If this is the case, some of the items on the CBCL may reflect this narrowed range of physical and social activities. It is worth noting, that Daltroy and colleagues (1992) found that there was no effect of family size, which they hypothesised might broaden the parent experience and give them more realistic expectations. Thus they felt that the parent reports did accurately reflect a slightly increased incidence of behavioural problems.

1.3 Locus of control

1.3.1 The concept of locus of control

The concept of 'locus of control' was first proposed by Rotter (1954, 1966). Rotter's social learning theory (1954) describes how the likelihood of an individual engaging in a particular behaviour is dependent on the interaction between reinforcement of the behaviour and how much this reinforcement is valued by the individual. Locus of control theory describes the beliefs held by individuals regarding outcomes and operates at general as well as specific levels. Rotter's theory made the distinction between internal and external locus of control beliefs. People with an internal locus of control believe that events or outcomes are more contingent on their own actions, whereas an external locus of control assumes that events or outcomes, are less influenced by personal action and more by forces such as luck or powerful others.

Lazarus and Folkman's theory (1984) stated that an individual's beliefs regarding their personal control of outcomes, and in particular threat, plays a key role in how they interpret and evaluate the threat. Empirical examination of Rotter's construct have indicated that people with an internal locus, in comparison to those with external

locus of control beliefs, are more likely to attempt to assert control over their environment, take responsibility for their own actions, seek out and assimilate pertinent information, demonstrate effective learning, and exhibit autonomous decision making (Phares, 1976; Strickland, 1978). External subjects have also been found to have more difficulty in adapting to major life events (Kilmann, Laval, & Wanlass, 1978) and display greater psychological symptomatology (Kno, Gray, & Lin, 1979). In general terms subjects who score higher in internal locus of control scales, tend to report less psychological and physical symptomatology (Joe, 1971)

1.3.2 Criticism of locus of control

Criticisms of the concept of locus of control when it has been assessed in relation to health behaviour, have mainly focused on two areas.

Firstly, the validity of the scales were low. In line with Rotter's (1975) assertion that prior experience in a given situation will enable situation specific beliefs to be utilised, situation specific measures seemed justified. Secondly, the unidimensional scoring of the locus of control scales (i.e. internal versus external) was questioned (Collins, 1974; Levenson, 1974). Levenson argued that the external locus could be further subdivided into control by chance as well as powerful others.

In response to these criticisms the Multidimensional Health Locus of Control Scale (MHLC) was developed (Wallston, Wallston, & DeVillis, 1978) and is the most widely used measure in the prediction of health behaviours (Wallston, 1992).

1.3.3 Locus of control modified for health

The study of individuals' likelihood to engage in health related behaviours has been a concern of health psychologists for many years. In particular, much research has investigated the contribution made by an individual's beliefs about health (Wallston, 1992). It comes as no surprise that cognitions regarding the control over one's health,

and especially the locus, or place of this control, have received the greatest interest (Wallston, 1989; Wallston, Wallston, Smith, & Dobbins, 1987).

Following the views raised by Rotter in 1975, that individuals' situational specific expectancies were more likely to predict behaviour in specific situations, Wallston and colleagues devised the Health Locus of Control Scale, in order to increase the predictability of locus of control when applied to individual behaviour in health situations (Wallston, Wallston, Kaplan, & Maides, 1976).

The application of social learning theory to the study of health behaviours assumes that the potential for a person to carry out certain health related behaviours is a multiplicative function of the belief held by the person that their actions will actually affect their health outcomes, as well as the degree to which the person values their health. The health value concept is seen as a moderating variable between health control beliefs and the engagement in health related behaviours by an individual (Wallston, 1992). In other words, if a person actually values a particular outcome *and* believes their actions can affect this, then they will engage in the health related behaviour to achieve this goal.

The original unidimensional scoring of the Health Locus of Control Scale (i.e. internal versus external) was found to be a better predictor of the behaviour of people within health-care settings, compared with the previous generic internal-external scale (Wallston et al, 1976; Wallston, Maides, & Wallston, 1976). This scale was later modified to the Multidimensional Health Locus of Control Scale, which encompassed the finding that the external scale was made up of two dimensions, those of powerful others and chance (Wallston et al, 1978; Wallston, 1989).

1.3.4 Locus of control in relation to children

Whilst there has been considerable interest in studying the control beliefs of adults there has been little such emphasis in children (Norwicki & Strickland, 1973). In terms of school achievement, belief in destiny has been identified as a significant determinant of mood status (Coleman, Campbell, Hobson, McPartland, Mood, Weinfeld, & York, 1966). Locus of control orientation has been found to be predictive of coping in school-aged children (LaMontagne, 1987).

Previous attempts to measure children's locus of control beliefs (for example, Bialer, 1961; Battle and Rotter, 1963) have not been entirely successful (for a review see Norwicki & Strickland, 1973). This led to the development of the Norwicki-Strickland Locus of Control Scale for Children (1973), which has been used extensively and assesses children's generalised health control beliefs.

Following suggestions by Rotter (1975), as well as Wallston and colleagues (Wallston, Maides, & Wallston, 1976), there has been a move to develop specific scales to measure health related locus of control, the emphasis being to develop specific scales for specific categories of behaviour. Parcel and Meyer, whilst developing their Children's Health Locus of Control Scale (Parcel and Meyer, 1978), summed up their rationale as based on the potential for using social learning theory to explain health behaviour, the importance placed on developing specific health locus of control scales, and the encouraging results obtained from use of adult health locus of control scales (Wallston, Wallston, & Kaplan, 1976; Wallston, Maides, & Wallston, 1976).

1.3.5 Health locus of control in childhood physical illness

The multifactoral models of health behaviour, which have been developed to counteract the “traditional” deficit centred approaches to chronic childhood illness, emphasise aspects of health behaviour which include children’s perceptions of their vulnerability, as well as their knowledge, beliefs and attitudes to illness (Perrin & Shapiro, 1985).

In this way, the importance of health control beliefs becomes clear, especially in terms of how effectively children with chronic illness understand, agree to and comply with their medical care. However, despite the importance placed on this concept, authors still call for additional research to investigate the nature of coping styles and health beliefs in children (for example Ioannou, 1991) and how these factors might affect psychological interventions with children suffering from chronic conditions.

Studies on children who are admitted to hospital for surgery have emphasized the importance that the concept of control played for these children (Jessner & Kaplan, 1949; MacKeith, 1953; Rose, 1973). Additional work has assessed the influence on children’s locus of control on their coping strategies. In general, an internal locus of control was associated with active coping strategies, such as information seeking (LaMontagne, 1984, 1987) and external locus of control was associated with avoidant coping strategies, such as denying worries (Rothbaum, Wolfer, & Visintainer, 1979; LaMontagne, 1984, 1987). LaMontagne (1993) concluded her review by proposing that coping interventions should focus on increasing children’s internal control beliefs, as control appears to be such an important feature during children’s hospitalisation.

In a further study on paediatric conditions, Perrin and Shapiro (1985) examined health beliefs in comparison to normal samples. The study found that children’s health beliefs undergo significant transformations around the ages of seven, nine and 13 years. Their findings largely supported previous research which identified that children suffering

from different paediatric conditions have different experiences. Individual chronic conditions have variable impacts on the children they affect.

The Perrin and Shapiro (1985) study revealed that children suffering from asthma and diabetes held health locus of control beliefs which did not differ from the normal population. On the other hand, children with a diagnosis of seizure disorder or an orthopaedic condition did appear to have less internal beliefs about their health. This is most likely due to the different nature of the conditions researched. Whilst asthma and diabetes are severe chronic diseases, the ability of the child to exert a degree of control over the disease process is more overt than unpredictable, uncontrollable conditions such as seizure disorders and orthopaedic problems. Perrin and Shapiro (1985) concluded that much more research needed to be carried out in to how health locus of control beliefs affect, and are affected by, individual chronic paediatric conditions.

1.4 Coping and locus of control

1.4.1 Integrating coping and locus of control

The present research is concerned with both concepts of coping and locus of control. As Petrosky and Birkimer (1991) point out, both are heavily implicated in psychological adjustment and thus it seems reasonable to “.... expect that these two measures would be related to each other as well” (page 337). The evidence that locus of control acts as a mediator influencing the relation between stress and outcome (see Parkes, 1984), suggests that personality influences the coping process (Kobassa, Maddi, & Kahn, 1982). Anderson (1977) discussed the finding that internals suffered less distress and functioned at a higher level than externals and concluded that this may be associated with their consistent use of more task-centred and fewer emotion-focused coping behaviours.

A study by Rao and colleagues (Rao, Subbakrishna, & Prabhu, 1990) concluded that, whilst locus of control orientation did not necessarily explain the experience and perception of life events per se, locus of control orientation did seem to play a part in the use of specific coping strategies. Further research has also identified the links between coping style and locus of control. Carver and colleagues (Carver, Scheier, & Weintrub, 1989) described a negative correlation between internal locus of control and emotion focused coping styles. In addition, Parkes (1984) reported that internals showed a higher frequency of direct coping and lower levels of suppression, whilst the opposite was true for subjects with an external locus of control orientation.

These results were largely confirmed by the study of Petrosky and Birkimer (1991). Both internal locus and direct coping, were negatively correlated with psychological symptom reporting. In addition, they were found to be closely related to each other. This suggests that successful adaptation to a childhood chronic illness may be associated with having an internal locus of control and use of direct coping strategies.

1.5 Theories of chronic childhood illness

1.5.1 An integrated theory of childhood chronic illness

What is clear from the above critique is that, whilst children who suffer from chronic physical illnesses may be at a higher risk of maladjustment, the considerable variability in their outcomes suggests traditional models of risk are inadequate. In their review article Wallander and Varni (1998) acknowledged that the emphasis of theoretical models of paediatric chronic physical illness had changed, resulting in “.... investigation of the risk and resistance factors that may explain these individual differences in adjustment to paediatric chronic physical disorders.” (P 31).

Two theoretical models have been proposed to explain these factors and conceptualise the myriad of factors which have been implicated in paediatric chronic illness. Specifically, the transitional stress and coping model (Thompson, Gustafson,

George, & Spock, 1994) and the risk and resistance model (Varni & Wallander, 1988; Wallander & Varni, 1992; 1995).

The framework underlying the transitional stress and coping model (Thompson, Gustafson, George, & Spock, 1994), uses concepts from ecological systems theory. The theory has been demonstrated to have some ability in predicting processes which contribute to the adjustment of children and mothers to chronic illness (Thompson & Gustafson, 1996).

The model identifies paediatric chronic illness as a potential stressor, to which the child attempts to adapt. The model theorises that psychosocial adaptational processes, such as expectations of self-esteem, health locus of control, coping behaviours, as well as maternal adjustment, combine with biomedical and developmental processes to influence the impact of the physical disorder. However the model has been criticised for being too narrow (Wallander & Varni, 1998) as it has only been empirically tested on sickle cell disease and cystic fibrosis. In addition, the range of factors which it incorporated is again quite limited.

The second, and more generic model, to be proposed for paediatric chronic illness is the risk and resistance model (Varni & Wallander, 1988; Wallander & Varni, 1992; 1995). In contrast to the transitional stress and coping model, it was directly designed to be applicable to the entire range of chronic physical disorders which afflict children.

Within the model, paediatric chronic illness is seen as an ongoing chronic strain for the child as well as the family. The authors use the definition of chronic strains as “.... persistent objective conditions that require continual adjustment, repeatedly interfering with the adequate performance of ordinary role-related activities” (Pearlin, Lieberman, Menaghan, & Mullan, 1981). The model utilises empirical findings which have been associated with the disease process. These concepts are hypothesised as *risk* and *resistance* factors which affect the adaptation to paediatric chronic illness.

Based on the original conception of the model (Varni & Wallander, 1988), Wallander and Varni (1998) describe the factors included in the model as follows. Firstly, the risk factors include disease/ disability parameters (such as diagnosis, handicap severity, medical complications, bowel/ bladder control, visibility, cognitive functioning, brain impairment), functional independence in the activities of daily living, and psychosocial stressors (for example disability-related problems, major life events, and daily hassles). Secondly, they report that the resistance factors include intrapersonal factors (such as competence, temperament, effectance motivation, and ability to problem-solve), social-ecological factors (family psychological environment, social support, family members' adaptation, and practical resources available for the family to draw on), as well as stress-processing factors (including cognitive appraisal and coping strategies).

One of the strengths of the model is its belief that these factors are *modifiable*. In this way the clinical relevance and applicability of the model is clear in guiding interventions for children suffering from chronic illness. The validity of the model has generally examined by testing of various subgroups of factors (for a review see Wallander & Varni, 1998) and has generally performed well, though some authors have suggested additional revisions (for example, Bradford, 1997).

1.6 Juvenile chronic arthritis

1.6.1 The extent of Juvenile Chronic Arthritis

The popular belief that arthritis is a condition which only affects older adults is unfortunately only a myth (Barlow, Shaw, & Harrison, in press). Juvenile Chronic Arthritis is a chronic, persistent condition which affects approximately 1 in 1000 children in the United Kingdom (Ansell, 1996). Recent figures suggest that over 15,000 children are currently known to suffer from Juvenile Chronic Arthritis (Arthritis and Rheumatism Council for Research, figures for 1994). Juvenile chronic arthritis is defined as manifesting itself before the child reached the age of 16 years (Munthe, 1990) and, in general, affects twice as many girls as it does boys (Varni, Walco, & Katz, 1989a). The peak onset of the disease occurs between the ages of 1-3 and 8-12 years (Varni et al, 1989a). The aetiology of arthritis is currently unknown and throughout the literature there appears to be no clear indication that it is an inherited illness. In America and Canada the condition is named Juvenile Rheumatoid Arthritis, whilst it can also be termed Juvenile Chronic Polyarthritis.

Juvenile chronic arthritis is characterised by persistent inflammation of the joints (Munthe, 1990) and can be divided into a number of sub-categories. The first form is Systemic Illness, in which arthritis is combined with fever and rash. In this case, the fever is the first symptom to emerge and is usually associated with modest arthritis. The second category is Polyarthritis, in which more than four joints are inflamed. Thirdly, the most common form of Juvenile Chronic Arthritis is Pauci-articular Arthritis and affects approximately two-thirds of children with arthritis. In this case, children have four joints or fewer which are affected or only one (Monarticular Arthritis). The fourth form is Juvenile Spondylitis, which is a rarer type occurring mainly in boys. This usually affects one or two joints of the legs. The final sub-category is Adult-type Rheumatoid Arthritis, which affects the small joints of hands and feet. This condition mainly arises in girls aged 11 years and upwards.

Treatment cannot target the cause of the disease, as the aetiology is unclear. Thus, the management of the disease is aimed at symptom reduction, attempts to slow the progression of the condition and long term prevention of physical disability. This is accomplished through a combination of pharmacology, physiotherapy and surgery. In addition, children are often required to use assistive devices, splints, and behavioural instructions.

1.6.2 The effects of Juvenile Chronic Arthritis

As in many paediatric chronic conditions, the primary responsibility for the management of the disease is commonly attributed to parents. Programmes are often time consuming and complex and can severely intrude into the normal daily activities of the family. In addition to the practical demands of the illness and its management, parents are faced with the realisation their child may have a limited life expectancy, be faced with severe pain, face emotional problems, and have limitations placed on their current ability, as well as the potential long term functioning (Eiser, 1993). Alongside this, the parents must also look after the needs of siblings, whilst maintaining family, social and work commitments (Eiser, 1993). Despite this seemingly daunting array of responsibilities, and consistent with the nature of more recent research, only a minority of parents experience significant difficulties (Elander & Midence, 1997; Silver, Bauman, & Ireys, 1995).

The long-term prognosis in Juvenile Chronic Arthritis depends on the type and severity of the individual child's condition. However, it can last from months to many years. Juvenile chronic arthritis follows an unpredictable course and thus children and families must cope with a cycle of fluctuations between active disease and periods of remission. Typically, children present with symptoms which can include pain, stiffness, swollen joints, fatigue, lack of appetite and general irritability (Barlow et al, in press). It has been estimated that a child who suffers from arthritis may lose up to one third of their free time as a consequence of the disease (Southwood & Malleon, 1993).

Particularly poor prognosis exists for a child whose arthritis recurs and whose joints are increasingly severely affected each time this happens. Research has indicated that children who suffer from a chronic illness with physical complications, are at an increased risk of displaying psychological disturbance (Cadman, Boyle, Szatmari, & Offord, 1987). As with other chronic illnesses, a child suffering from Juvenile Chronic Arthritis will face many hospital appointments and, particularly in relation to Juvenile Chronic Arthritis, blood tests and possibly steroid injections to reduce inflammation.

1.7 Pain in children

1.7.1 Chronic and recurrent pain in childhood illness

Pain has been defined as “.... an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of damage” (Merskey, 1986, p 217). As Eiser (1990b) acknowledges, the issues related to experience of pain in children have traditionally received little attention. It has even been suggested that children do not experience pain, or at least less so than adults. Fortunately, this viewpoint has been successfully challenged, so that it is now acknowledged that neonates and infants experience pain sensations.

Despite this there are still concerns currently raised regarding the attention children's pain receives. For example, Schechter and colleagues (Schechter, Allen, & Hanson, 1987) compared the use of analgesia between children and adults with similar conditions. They highlighted that, on average, adults received 2.2 doses of narcotics per day, whilst the children received 1.1 doses per day. The authors concluded that medical staff may be less likely to recognise discomfort and pain in children than in adults.

The importance of assessing and treating pain in children with Juvenile Chronic Arthritis has been recently well acknowledged (see Varni, Walco, & Katz, 1989a; Varni, Walco, & Katz, 1989b). Pain in children has been described as:-

“.... a complex cognitive developmental phenomenon, involving a number of biobehavioural factors that interact to produce differential levels of pain perception and verbal and nonverbal manifestations.” (Varni et al, p 56).

Varni (1983) points out that when considering paediatric pain one should distinguish between acute, chronic, and recurrent pain. Acute pain is the body's warning signal of injury or disease. It functions as part of the system which helps us avoid harm and is accompanied by an anxiety reaction closely related in time to its cause. It is this latter symptom which separates acute from chronic pain, which is more associated with reactive features such as compensatory posturing, lack of developmentally appropriate behaviours, depressed mood, inactivity or restriction of day to day activities which can be maintained independently of the original tissue damage (Varni et al, 1989).

Recurrent pain refers to the type of pain experience in which the clear distinction described above between acute and chronic episodes, cannot be made. Varni and colleagues (1989a; 1989b) state the pain associated with Juvenile Chronic Arthritis falls into the chronic pain category, whilst the episodic pain of acute bleeding episodes in children suffering from hemophilia and sickle cell disease, is more associated with the type of pain described by recurrent episodes.

1.7.2 The assessment of pain in children

In the assessment of adult pain, the most widely used measure (Varni et al, 1989) is that developed by Melzack, the McGill Pain Questionnaire (Melzack, 1975). In an attempt to promote the study of acute, chronic and recurrent pain in children, Varni and colleagues (Varni, Thomson, & Hanson, 1987) used the McGill Pain Questionnaire as the basis for a multidimensional assessment tool for children, now referred to as the Varni-Thomson Pediatric Pain Questionnaire (PPQ).

For the development of the Pediatric Pain Questionnaire, it was necessary to be aware of and take into account the cognitive-developmental conceptualisations of children. The Pediatric Pain Questionnaire goes a long way to standardise the assessment of children's pain, by using visual analogue scales to assess the intensity of the pain experience. Visual analogue scales provide a continuous line, anchored at either end with appropriate descriptors, with the respondent asked to place a mark on the continuum at which they feel their personal perceptions fall. In the Pediatric Pain Questionnaire the anchors are developmentally appropriate descriptors of pain, such as "not hurting"/ "hurting a whole lot", as well as the additional use of happy and sad faces.

In studies of the use of visual analogue scales with children, it has been reliably demonstrated that they do appear to accurately assess the pain experience of children (Varni, Thomson, & Hanson, 1987; McGrath, 1986; McGrath, de Verber, & Hearn, 1985; McGrath & de Verber, 1986). Whilst it has been shown within these papers that children's self report visual analogue scales correlate with parent and physician ratings of the child's pain, the validity of using child self report has been questioned by some authors, given that they do not always correlate with adult observer estimates (Varni et al, 1989).

However, Varni and colleagues (1989a; 1989b) point out that it is possible for children to experience pain without displaying overt verbal and non-verbal indicators.

Pain is in essence a subjective experience, and thus it cannot be exactly assessed by another who is not part of that experience. Varni and colleagues remind us that in the adult literature, correlations between pain reports of adult patients with nurse observers on visual analogue scales can be as low as $r = 0.38$ (Teske, Dart, & Cleeland, 1983), yet this does not immediately lead us to question the validity of the adult patients' self reports! Varni and colleagues (1989a) sum up their views by saying that "... children should be accorded the same degree of consideration; i.e. they are the best judges of their pain experience." (P 58).

1.7.3 Pain and coping in Juvenile Chronic Arthritis

Pain is one of the most consistently reported features in studies of children with arthritis (Hagglund, Schopp, Alberts, Cassidy, & Frank, 1995) and is a priority concern, not only for affected children, but for their siblings and parents as well (Konkol, Lineberry, & Gottlieb 1989). Lovell and Walco (1989) found pain to a significant predictor of adjustment to Juvenile Chronic Arthritis. In addition, pain is reported to explain a significant amount of the variance in social functioning, activities of daily living and school performance (Varni, Wilcox, Hanson, & Brik, 1988).

Studies of pain in Juvenile Chronic Arthritis have reported variable results (Ross, Lavigne, Hayford, Berry, Sinacore, & Pachman, 1993). They attribute possible causes to be sample differences and differences in measuring pain. However, the study does state that "... disease activity alone has not been sufficient to explain reported levels of pain among patients with JRA." (P 562). This statement suggests that psychological factors have an important part to play in accounting for the pain experience in Juvenile Chronic Arthritis and is supported by the results of the Ross and colleagues study (1993).

In the adult literature, pain is also reported to be the most debilitating concern of rheumatoid arthritis patients (for example, Lerman, 1987). In explaining the variable outcomes reported in the literature, patients' coping strategies have been hypothesised

as moderators of the experience of pain (Beckham, Gustafson, May, & Annis, 1987). Further research in this area has revealed that passive coping strategies are associated with higher depression levels (Brown, Nicassio, & Wallston, 1989), whilst rational thinking (an active strategy) is associated with lower reported helplessness, daily hassles, global distress and current pain intensity (Parker, Smarr, Buescher, Phillips, Frank, Beck, & Walker, 1989).

As identified previously, the risk and resistance model (Wallander et al, 1989) has formed the basis of much recent research. The model is based on substantial research using multiple regression analysis to statistically predict pain report and functional status in children with Juvenile Chronic Arthritis (Varni, Thomson, & Hanson, 1987; Thomson, Varni, & Hanson, 1987; Varni, Wilcox, Hanson, & Brik, 1988). Using pain report as measured by the Pediatric Pain Questionnaire as the criterion variable, it was found that the predictor variables of children's psychological adjustment, family psychosocial environment, and disease parameters, explained 72% of the variance in children's self report of worst pain for the preceding week. Further research into the nature of Juvenile Chronic Arthritis, has reinforced the assertion that this model has some validity in predicting adaptation to the disease (Timko, Stovel, Moos, & Miller, 1992), and is easily applicable to the increasing evidence that psychological factors have much to contribute in the explanation of the variance in outcomes of children suffering from a chronic illness.

However, little is in fact known about the coping strategies and cognitive beliefs children use to effectively cope with Juvenile Chronic Arthritis (Jaworski, 1993). Identifying these key factors, and how they relate to successful outcome, will enable clinicians to identify those children who are at risk of maladjustment. In other words, identifying children who cope well, will enable us to more effectively help those children who are having problems (Jaworski, 1993).

1.8 The basis of the present research

1.8.1 General points

The above introduction has detailed the importance of coping and locus of control beliefs when considering adaptation to chronic illness. The present study is concerned with identifying the specific patterns of strategies and beliefs which might be associated with improved functioning of children with Juvenile Chronic Arthritis. The aim is to better understand the factors associated with successful adaptation, in order to intervene effectively with children who are having difficulties coming to terms with Juvenile Chronic Arthritis.

In addition, there are several important factors, drawn from the theory and research described above, which have influenced the design of this research. These are briefly described below.

1.8.2 The range of factors to be studied

Factors incorporated within the risk and resistance model have been included within the study. In addition, the study by Hagglund and colleagues (1995), concluded that research into pain in children with arthritis, should also take into account several other factors. Specifically, research design should encompass *current* pain, depression, anxiety, as well as measures of self concept. All these factors will be included in the present research in an attempt to gain the most accurate picture.

However, whilst demographic variables will be collected during the study, their relative importance may be quite low. This assumption is based on the finding of various authors that, when considering the coping strategies and adjustment of children to chronic conditions, demographic variables did not contribute significantly to the variance in outcomes. For example, Beckham and colleagues (Beckham, Keefe, Caldwell, & Roodman, 1991) reported that demographic variables were less

important than the patients' own coping strategies, whilst Olson and colleagues (Olson, Johansen, Powers, Pope, & Klein, 1993) showed that that disease severity did not significantly affect the use of cognitive coping strategies. The relative merits of this approach are discussed in the methodological discussion in the concluding section of this research, especially in relation to sample size.

1.8.3 The study of pain within a community sample

In her review of the research literature on the psychological effects of childhood chronic disease, Eiser (1990b) highlighted that there has been an overemphasis on studying those children who fail to cope with the disease process. In this way, it is not surprising that research has identified increased maladjustment. Eiser calls for an increasing recognition that some children do cope effectively with highly aversive situations. The present research attempts to address this issue by sampling from a community sample of children attending a hospital out-patient clinic, not from those children referred to psychological services for support.

As reported previously, during the development of KIDCOPE (Spirito, Stark, & Williams, 1988; Spirito, Stark & Tyc, 1989) it was attempted to assess the different aspects of coping in children. Stark, Spirito & Tyc (1991) found that over 50% of their paediatric hospital sample reported other factors which were associated with the hospital stay itself (e.g. lack of privacy, poor food), as their primary concerns, not the experience of pain. They concluded that research should focus beyond the simple investigation of coping strategies used for pain.

However, a concurrent study by Beckham and colleagues (Beckham, Keefe, Caldwell, & Roodman, 1991) on patients from an out-patient clinic concluded that pain in rheumatoid arthritis (RA), as well as strategies to cope with pain, were key factors. They concluded that "... given the problems that many RA patients have with pain, further investigation of the role of coping and pain coping skills training interventions appears warranted." (P 122). It is also worth noting that, during hospital admission

for treatment purposes, children with Juvenile Chronic Arthritis are extremely well managed medically and thus are unlikely to report high levels of pain at that time.

In addition, Bradford (1997) notes that there has been an over-emphasis on assessing children in hospital settings. He points out that most children suffering chronic disease live at home most of the time, accessing community facilities. Studies of hospitalised children may well produce different results as a consequence of their placement. In this way the present research will focus on a community sample of children with Juvenile Chronic Arthritis.

1.8.4 Within-group design

The debate regarding the need for control groups in research into chronic illness has existed for some time. As reported previously authors such as Lemanek and colleagues (1986) have criticised studies for their lack of appropriate use of control groups of healthy peers. Moise (1986) stressed the need for research to go beyond simple comparisons of chronically ill children and 'normals', to encompass other groups of children diagnosed with chronic illness. Moise argues that the former method risks incorrect assumptions that particular characteristics are specific to one form of illness, rather than as a general characteristic associated with the stresses of all chronic illnesses.

In contrast, Hurtig and White (1986) have argued for a 'within-group' approach to research on children with chronic illnesses. They argue that comparison with controls fails to address the important issues associated with positive psychological functioning and successful adaptation. In writing about sickle cell disease they write that one needs "..... a 'within group' study to isolate specific variables that would encompass the resultant problems and the way they affect the patient's response and the course of the illness itself." (p. 30).

Further weight is added to the argument for a within-group approach by the situation-specific results of cognitive coping strategies with children in the Olson and colleagues study (Olson et al, 1993). The fact that children with chronic illnesses may learn specific strategies for events related to their illness, but may not generalise these strategies to other areas, suggests that studying coping strategies within individual disease populations is most appropriate. Midence (1994) pointed out that strategies specific to one chronic illness may not necessarily apply to others. Indeed, conditions such as diabetes which lack the degree of pain and visible disability of Juvenile Chronic Arthritis, suggest that diabetic children have less need to develop cognitive coping strategies (Olson et al., 1993). This view is theoretically backed up by Lazarus (1993) who has urged that the study of coping should shift to examining coping in specific situations. This assertion has been discussed above.

The present research does not incorporate a control group for the reasons detailed above. However, it should also be noted that the measures used within the study have been standardised on healthy children (see section 2). Thus, it will be possible to for comparisons to be made with normative data.

1.8.5 Children's self report

Ennett and colleagues (Ennett, DeVellis, Earp, Kredich, Warren, & Wilhelm, 1991) have pointed out that the majority of research into the adjustment of children suffering from Juvenile Chronic Arthritis has relied on the use of parental and teacher reports, as well as reference to disease severity. This method relies on the implicit assumption that parental reports accurately reflect the impact of disease on the child. However, it is increasingly obvious that researchers need to survey children's direct reports of their adjustment and widen the field of study beyond disease severity (for example Varni, Wilcox, & Hanson, 1988; Wallander, Varni, Babani, Banis, & Wilcox, 1988).

Empirical research in the field of Juvenile Chronic Arthritis, which has compared children's and mothers' reports, has found that whilst there was general agreement on

the pain and disability associated with arthritis, parents over-reported the psychological impact, in terms of mood and psychological symptoms (Billings, Moos, Miller, & Gottlieb, 1987). Further research demonstrated that children and their mothers reports of perceived competence and the child's disease experience can differ (Ennett et al, 1991). In Ennett and colleagues study, mothers rated the child more negatively, whilst reporting greater psychological defects than their child's self-report. The study concluded that it is vital to take into account the child's own perceptions about their disease experience. The present research aims to use this finding as justification for primarily surveying the beliefs and self-reports of children themselves.

1.9 The aims of the present research

The present research is primarily concerned with the contribution that both coping style and health locus of control beliefs play in the status of children suffering from Juvenile Chronic Arthritis living in a community setting, who receive their treatment on an out-patient basis.

For the basis of this research, outcome was examined by measuring children's self reports of pain, anxiety, self-esteem and depression. In addition, and designed to provide an alternative, objective (i.e. in addition to the child's perspective) measure of status, parents were asked to provide information regarding their child's behaviour.

1.9.1 Hypotheses

Based on the predictions made by the theoretical standpoints advocated above and in conjunction with the results that can be taken from the wealth of research reported within this introduction, the present study has made the following predictions about the potential results from this investigation:-

1.9.2 Hypothesis 1

The first hypothesis predicts that the use of coping strategies, as assessed by the KIDCOPE, will explain a significant proportion of the variance found in terms of reported pain and self reported health status in terms of anxiety, self-esteem, and depression, as well as parental reports of behavioural problems. Specifically this will include the following predictions:-

1(a) Positive/ approach coping strategies will be associated with lower reported pain and better perceived health status (anxiety, self-esteem, depression), as perceived by children suffering from Juvenile Chronic Arthritis.

1(b) Positive/ approach coping strategies will be associated with lower reports of behavioural maladaptation as assessed by parental report of their children.

1(c) Negative/ avoidance coping strategies will be associated with higher reported pain and poorer perceived health status, as perceived by children suffering from Juvenile Chronic Arthritis.

1(d) Negative/ avoidance coping strategies will be associated with higher reports of behavioural maladaptation as assessed by parental report of their children.

1.9.3 Hypothesis 2

As detailed in section 1.3, the second hypothesis predicts that locus of control, assessed by the Children's Health Locus of Control Scale, will explain a significant proportion of the variance found in terms of reported pain and self reported health status. This study makes the following predictions about the nature of this contribution:-

2(a) Internal locus of control will be associated with lower reported pain and better perceived health status (anxiety, self-esteem, and depression) by children with Juvenile Chronic Arthritis.

2(b) Internal locus of control will be associated with lower reports of behavioural symptomatology by the parents of children with Juvenile Chronic Arthritis.

2(a) External locus of control, both chance and powerful others, will be associated with higher reported pain and worse perceived health status (anxiety, self-esteem, and depression) by children with Juvenile Chronic Arthritis.

2(b) External locus of control, both chance and powerful others, will be associated with higher reports of behavioural symptomatology by the parents of children with Juvenile Chronic Arthritis.

1.9.4 Hypothesis 3

The third set of predictions made by this research concern the relationship between coping style and health locus of control beliefs.

3(a) Positive/ approach coping strategies will be associated with internal locus of control.

3(b) Negative/ avoidance coping strategies will be associated with the external orientations of chance and powerful others.

1.9.5 Hypothesis 4

4(a) As children's age increases, more positive/ approach coping strategies will be used by children.

4(b) As age increases, children will develop a more internalised locus of control.

1. Method

1.1 Design

This study is essentially a cross sectional examination of children's coping and health beliefs utilising within group comparisons of a population of children diagnosed with Juvenile Chronic Arthritis. Analysis is primarily orientated toward correlational design.

The study was granted ethical approval (subject to minor rewording changes in two of the American orientated measures) by the Lothian Research Ethics Committee, Paediatric subcommittee.

1.2 Subjects

Children and their families for the present study were selected from those attending the Rheumatology Out Patient Clinic based at the Royal Hospital for Sick Children, Edinburgh. The clinic team consists of a Consultant Rheumatologist and Consultant Paediatrician, with input from Physiotherapy, Occupational Therapy, Social Work, and Clinical Psychology.

1.2.1 Selection criteria

Suitable candidates for the research project were randomly selected from the Rheumatology Clinic by age. Children who were aged between 7 and 15 years of age were deemed appropriate for the measures included. In addition, all children selected for the study had to have one of the following diagnoses of Juvenile Chronic Arthritis:-

Systemic Illness, Polyarthritis, Pauci-articular Arthritis, Monarticular Arthritis, Juvenile Spondylitis, or Adult-type Rheumatoid Arthritis.

1.2.2 Exclusion criteria

At the suggestion of the Consultant Rheumatologist, children who had not been diagnosed for more than six months were ruled out of the study.

Any children who had a history of learning difficulties were excluded from the study. This decision was taken because the children's ability to understand the instructions for the self-report measures was essential.

Furthermore, children or families who were currently taking part in any other study were excluded. This meets the condition stipulated by the Lothian Research Ethics Committee, that it is desirable to ensure that families are not overburdened by research commitments.

Final inclusion numbers

Following the above selection and deselection criteria, and out of a final list of 50 possible candidates who met the age criteria, 38 families (76%) were approached by the author. Of the original 50, 12 children (24%) were excluded on the basis of time since diagnosis less than six months, history of learning difficulties, and the lack of definitive diagnosis of the above categories of Juvenile Chronic Arthritis.

Out of the 38 families who were asked to take part in the study, 6 (15%) were unable to participate due to time and distance constraints, one family (3%) felt that their child was in remission and declined to take part, and only one family (3%) refused to take part without reason. In the end, 30 children and their parent/parents, representing 79% of the possible population approached, agreed to take part in the study. Given the heavy burden placed on families of children with Juvenile Chronic Arthritis, this final figure represents an excellent uptake and reflects the commitment and interest these families typically display in clinical settings.

Procedure

Participants for the study were recruited via two methods.

Firstly, children and their parents were made aware of the study during their clinic visit and were given an information leaflet to read before they were asked to participate. The information leaflet described the rationale for the study, the nature of their participation and proposed use of the study for improved knowledge for clinical interventions. Following this, both children and parents were encouraged to ask questions, or raise any concerns, before being allowed to consider their participation. The family was then offered a further out patient appointment at the researcher's office, or a home visit, though some families elected to complete the study whilst they were waiting for their clinic appointment. Whilst this latter method was more convenient for the family, as they did not have to find time for additional appointments, the very hectic nature of clinic appointments as well as time constraints placed on the participants by the clinic appointment time, often meant that these sessions were more fraught. It appeared to the author that families who were seen outwith the out-patient clinic felt more involved in the study and seemed to gain more from their participation.

Secondly, families with children who fitted the inclusion criteria were contacted by telephone and made aware of the study. At this point they were sent an information sheet, described above, as well as an out patient appointment at the researcher's office. For families who expressed difficulty in attending such an appointment, they were offered a home visit. At the subsequent appointment or home visit, the expression of questions or concerns was encouraged.

Informed consent was sought from the parent of the child before the child was seen. This was encapsulated in the standard Lothian Research Ethics Committee Standard

Consent Form. In addition, verbal consent to participate in the study was always elicited from the children themselves.

The battery of children's measures was administered by the researcher with the child and in isolation from the parents. This was due to the observation from clinical practice that administering self report measures to children with parents present can be complex, as parents can intervene to correct responses they feel the child has given 'incorrectly'. Thus parents were asked to complete their part of the study in another room. The children's measures were always presented in the following order:-

Pain report

Varni-Thomson Paediatric Pain Questionnaire (Varni Thompson and Hanson, 1987)

Coping

KIDCOPE (Spirito, Stark & Williams, 1988; Spirito, Stark & Tyc, 1989)

Children's health locus of control

Children's Health Locus of Control Scale (Parcel and Meyer, 1978)

Measures of health status

Revised Children's Manifest Anxiety Scale (Reynolds and Richmond, 1994)

Self-Perception Profile for Children (Harter, 1985)

Children's Depression Inventory (Kovaks and Beck, 1977; Kovacks, 1981)

Childhood Behaviour Checklist (Achenbach & Edelbrock, 1983)

(These measures are displayed in full in Appendix II.)

Children were seen for an average of approximately 25 minutes, though the range was from 15 minutes to 70 minutes. The length of time for completion often relied on the level of assistance each child required. All children were offered complete support and indeed some children preferred to have the entire set of measures read to them.

1.4 Measures

1.4.1 Varni-Thomson Paediatric Pain Questionnaire Child Form (PPQ-Child)

Developed by Varni, Thompson and Hanson (1987), the Varni-Thomson Paediatric Pain Questionnaire comes in separate child and parent versions which are designed to be administered in a structured interview format. The child form, which is used in the present research, is designed to be completed within 10 minutes, whilst the parent form takes 15 to 20 minutes. The form is also designed to be sensitive to the cognitive/ developmental abilities of children.

The child form addresses the intensity of both current and worst (in the last week) pain on visual analogue scales which are 10cm long. The pain intensity is measured as the length of the mark made by the child from the left edge of the analogue scale. This gives a 'score' for pain from 0= no pain to 10= severe pain. Children are asked to mark on the two scales (a) "how you feel now" and (b) "the worst pain you had this week". In addition, children are asked to describe the pain or hurt in their own words, as well as choose colours to represent 'No pain', 'Mild pain', 'Moderate pain', and 'Severe pain' and use these to colour figural representations of their body indicating where they experience the differing levels of pain. These additional items allow the assessment of sensory, affective and evaluative aspects of the child's individual pain experience, which are used to give a more detailed descriptive picture of the pain, though are not scored formally.

The initial study by Varni and colleagues (1987) reported data on children with Juvenile Chronic Arthritis, their parents and doctors. Construct validity was demonstrated with reference to the correlations found between the pain intensity ratings of the children, parents and doctors, when compared to independent measures of disease activity. Correlations for inter-rater reliability lie within the satisfactory limits of 0.54 to 0.85. In addition, Walco, Varni, and Ilowite (1992) provided

evidence for short and long term sensitivity of the measure to change following a cognitive-behavioural treatment package.

1.4.2 KIDCOPE

The KIDCOPE (Spirito, Stark & Williams, 1988; Spirito, Stark & Tyc, 1989) is a self report questionnaire assessing the coping strategies employed by children when coping with adverse conditions. The KIDCOPE comes in a younger form version for children seven to 12 years of age, as well as an older version (13 to 18 years). The KIDCOPE requires less than ten minutes to administer. For consistency the younger version was used for all subjects within the present research.

The KIDCOPE assesses the frequency and perceived effectiveness of ten commonly used cognitive and behavioural strategies. Children are asked to describe an unpleasant experience associated with their illness and then indicate whether they utilised any of the commonly used coping strategies. In the present study, which is concerned with the experience of pain, the wording of this statement was:-

“We are trying to find out how children deal with the problems related to their arthritis. Think about the worst pain you had this week, which you described on the previous page.”

The young children’s measure is made up of 15 items which are detailed below.

Distraction:- 1. “I just tried to forget it.” &

2. “I did something like watch TV or played a game to forget it.”

Social withdrawal:- 3. “I stayed by myself.” &

4. “I kept quiet about the problem.”

Cognitive restructuring:- 5. “I tried to see the good side of things.”

- Self-criticism:- 1. "I blamed myself for causing the problem."
- Blaming others:- 2. "I blamed someone else for causing the problem."
- Problem-solving:- 3. "I tried to fix the problem by thinking of answers." &
4. "I tried to fix the problem by doing something or talking to someone."
- Emotional regulation:- 5. "I shouted, screamed or got angry." &
6. "I tried to calm myself down."
- Wishful thinking:- 7. "I wished the problem had never happened." &
8. "I wished I could make things different."
- Social support:- 9. "I tried to feel better by spending time with others like family, grown-ups, or friends."
- Resignation:- 10. "I didn't do anything because the problem couldn't be fixed."

These items are then used to calculate the 10 strategies which the KIDCOPE aims to assess. A child is given a score of 1 if he or she indicates they use the strategy, 0 if not. On categories with two items, the child is given a score of 0 if neither item is used and 1 if either or both items are indicated. The child rates whether they used the coping strategy and then is asked to rate how effective they felt the strategy to be. The KIDCOPE also converts into two further subscales. Specifically, Positive/ approach (consisting of cognitive restructuring, problem-solving, emotional regulation, and social support) and Negative/ avoidance (calculated from distraction, blaming others, wishful thinking, and resignation).

The original study reported test-retest reliability scores up to 0.83 and validity between 0.55 and 0.77. Unfortunately, no formal investigation has yet been made of the effectiveness scale on the KIDCOPE. Thus, whilst the data was collected for this study, no present attempt was made to analyse the information contained within.

1.4.3 Children's Health Locus of Control Scale (Child HLC)

Designed by Parcel and Meyer (1978) the Children's Health Locus of Control Scale (Child HLC) is a 20 item scale specifically designed for the measurement of children's beliefs about their control over health issues. The scale is designed to be completed within 10 minutes.

The scale consists of 3 practice items, followed by the 20 scale items. The instructions given to children are as follows:-

"We would like to learn about different ways children look at their health. Here are some statements about health or illness (sickness). Some of them you will think are true and so you will circle YES. Some of them you will think are **not** true and so you will circle the NO."

Each item in the scale itself, is a statement about factors influencing health, for example "I can do many things to fight illness". The child is asked to respond in a yes/no format whether they consider the statement to be true or false for themselves.

The scale encapsulates both the unidimensional and multidimensional scoring formats. The unidimensional scoring is 1 in the internal direction and 0 in the external direction. For this scoring format the following items are scored in the negative direction (i.e. a score of one corresponding to an answer of "NO"):-

1, 3, 4, 5, 6, 7, 8, 10, 12, 13, 14, 15, 17, 18.

The multidimensional scale is scored to reflect the factors of internal control, for example "I can do things to keep from being sick", powerful others control, for example "I can only do what the doctor tells me to" and chance control, for example "Bad luck makes people sick". Items corresponding to the three subscales are detailed below.

Internal:- 2, 9, 11, 16, 19, 20

Powerful others:- 4, 7, 8, 12, 13, 14, 15, 17, 18

Chance:- 1, 2, 5, 6, 10

The study by Parcel and Meyer (1978) tested the internal consistency of the scale and found an overall reliability coefficient of 0.753 in their sample, as well as a six week test-retest reliability of 0.62. Factor analysis revealed 11 items clearly loading on the three subscales, with one loading on two subscales. This led to a reworded measure which is used in the present study. A replication study by O'Brien, Bush and Parcel (1989) demonstrated evidence for construct validity of the scale.

1.4.4 Revised Children's Manifest Anxiety Scale (RCMAS)

The Revised Children's Manifest Anxiety Scale (RCMAS) is subtitled "What I Think and Feel" and was developed by Reynolds and Richmond (1994). The scale is a 37 item self report measure for children aged 6 to 19 years of age, assessing the level and nature of anxiety in children and adolescents. The measure takes less than 10 minutes to administer.

The Revised Children's Manifest Anxiety Scale gives the instruction:-

"Here are some sentences that tell how some people think and feel about themselves. Read each sentence carefully. Circle the word "YES" if you think it is true about you. Circle the word "NO" if you think it is **not** true about you..... There are no right or wrong answers. Only you can tell us how you think and feel about yourself."

The respondent answers each of the 37 statements about common symptoms of anxiety, by circling 'Yes' or 'No'. If they think the item applies to them then they circle 'Yes' and receive a score of 1 for that item. The 'Yes' responses are summed to provide a total anxiety score. However, the RCMAS is also designed to provide four



further subscales for additional information. These are physiological anxiety, worry/ oversensitivity, social concerns/ concentration, as well as a lie scale. The latter is designed to identify if the child is 'faking good' by under-reporting symptoms. Examples of questions fitting into the various subscales are detailed below:-

Total anxiety:- "I have trouble making up my mind"

Physiological anxiety:- "Often I feel sick in my stomach"

Worry/ oversensitivity:- "I get nervous when things do not go the right way for me"

Social concerns:- "I feel that others do not like the way I do things"

Lie:- "I am always nice to everyone"

The 37 items on the scale are scored in the subscales in the following ways:-

Total anxiety:- 1, 2, 3, 5, 6, 7, 9, 10, 11, 13, 14, 15, 17, 18, 19, 21, 22, 23,
25, 26, 27, 29, 30, 31, 33, 34, 35, 37

Physiological anxiety:- 1, 5, 9, 13, 17, 19, 21, 25, 29, 33

Worry/ oversensitivity:- 2, 6, 7, 10, 14, 18, 22, 26, 30, 34, 37

Social concerns:- 3, 11, 15, 23, 27, 31, 35

Lie:- 4, 8, 12, 16, 20, 24, 28, 32, 36

The psychometric properties of the RCMAS have been reported by Reynolds and Richmond (1994). For the total anxiety scale an internal consistency of 0.83 in a test development sample of 329 children. Reliability estimates for the various subtests range from the 0.50s to the 0.80s. Reynolds (1981a) reported a test-retest reliability coefficient of 0.68 for total anxiety scores of 534 children over a nine month period. Reynolds (1980a) found considerable evidence for the construct validity of the RCMAS. He found a coefficient of 0.85 with the trait scale of the State-Trait Anxiety Inventory for Children (Spielberger, 1973).

1.4.5 Self-Perception Profile for Children (SPPC)

Developed by Harter (1982, 1985) the Self-Perception Profile for Children (SPPC), which is subtitled “What I am like”, assesses children’s perceived competence in a number of areas. The 36 item scale is administered as a self report measure for children over the age of 7 years and takes approximately 10 minutes to administer.

Each of the items requires children to choose which of two conflicting statements they feel applies to themselves, for example “Some kids wish their body was different *but* other kids like their body the way it is”, and then decide whether the statement is “Sort of” or “Really” true for them. Each item is scored on a four point ordinal scale. The items then are converted into six subscales, consisting of six items. The subscales are global self-worth, scholastic, social acceptance (such as popularity and acceptance with peers), athletic competence, physical attractiveness, and behaviour. For this study, the individual items were summed to provide a total score for each subscale, with a higher score corresponding to a higher self-concept. Items which are scored in the negative direction are, 1, 3, 4, 7, 8, 10, 11, 15, 17, 18, 20, 21, 24, 25, 30, 32, 34, 35.

Examples of statements corresponding to the subscales are provided below:-

Global self-worth:- Some kids are often unhappy with themselves

BUT

Other kids are pretty pleased with themselves

Scholastic:- Some kids feel they are just as clever as other kids

BUT

Other kids aren’t so sure and wonder if they are as clever

Social acceptance:- Some kids have lots of friends

BUT

Other kids don’t have very many friends

Athletic competence:- Some kids do very well at all kinds of sports
 BUT
 Other kids don't feel they are good when it comes to sports

Physical attractiveness:- Some kids are happy with the way they look
 BUT
 Other kids are not happy with the way they look

Behaviour:- Some kids often do not like the way they behave
 BUT
 Other kids usually like the way they behave

The items which are scored on the measure for the subscales are:-

Global self-worth:- 6, 12, 18, 24, 30, 36
 Scholastic:- 1, 7, 13, 19, 25, 31
 Social acceptance:- 2, 8, 14, 20, 26, 32
 Athletic competence:- 3, 9, 15, 21, 27, 33
 Physical attractiveness:- 4, 10, 16, 22, 28, 34
 Behaviour:- 5, 11, 17, 23, 29, 35

Harter (1982, 1985) reported good psychometric properties for the measure, with high internal consistency, test-retest reliability and a stable factor structure. Cronbach's alpha reliability values ranged between 0.71 for the behaviour subscale, to 0.86 for the athletic subscale. Factor analysis showed that five of the six subscales (global self worth was more variable between individuals) were distinct, with cross loadings across factors between 0.04 and 0.08.

The Self-Perception Profile for Children has been modified for use in this country and standardised on 4282 school aged children in the Lothian region of Scotland (Hoare, Elton, Greer, & Kerley, 1993). This study uses this modification for the United Kingdom as the original contains words and phrases specific to American children.

Hoare and colleagues (Hoare, Elton, Greer, & Kerley, 1993) made the following changes to the Self-Perception Profile for Children (Harter, 1982; 1985).

- Question 1 “school work assigned to them” to “their school work”
- Question 7. “just as smart as other kids their own age” to “just as clever as other kids”
- Question 7. “wonder if they are as smart” to “wonder if they are as clever”
- Question 15. “well at just about any new sports activity they haven’t tried before” to “well at any new sport”
- Question 15. “may not do well at sports they haven’t ever tried” to “do not do well at new sports”
- Question 17. “act” to “behave”
- Question 21. “better than others their age at sports” to “better at sports than their friends”
- Question 22. “Some kids wish their physical appearance (how they look) was different” to “Some kids wished they looked different”
- Question 22. “Other kids like their physical appearance the way it is” to “Other kids like the way they look”
- Question 31. “Trouble figuring out the answers at school” to “trouble working out the answers at school”
- Question 31. “figure out” to “work out”

1.4.6 Children’s Depression Inventory (CDI)

Developed by Kovacs and Beck (1977) and Kovacs (1981), the Children’s Depression Inventory is a 27 item self report measure used to aid diagnosis of depression in children by assessing the affective, cognitive and behavioural symptomatology of depression. The scale is standardised for children between the ages of eight and 13 years of age and takes approximately ten minutes to administer. The CDI has also been administered in a short form version (Carlson & Cantwell, 1980). The instructions accompanying the Children’s Depression Inventory are as follows:-

“Children sometimes have different feelings and ideas. This form lists the feelings and ideas in groups. From each group pick *one* that describes you best for the past two weeks.”

Each item on the scale consists of three descriptors which increase in severity of depressive symptomatology, examples of these are:-

“Sometimes I think that bad things will happen to me”, “I worry that bad things will happen to me”, “I am sure that terrible things will happen to me”.

“My looks are fine”, “There are some funny things about my looks”, “I look ugly”

“My schoolwork is fine”, “My schoolwork is not as good as before”, “I do very badly in subjects I used to be good at”.

Children are asked to indicate which of the three descriptors most applies to the way they have been feeling within the past two weeks. Items are scored on a three point scale from 0 to 2, with 2 representing the most severe form of the particular symptom of depression. Scores are then summed to provide a total depression score. Items which are scored negatively on the Children’s Depression Inventory (i.e. those which are presented on the measure with the first of the symptom descriptors representing the most severe form of the depression symptomatology) are the following:-

2, 5, 7, 8, 10, 11, 13, 15, 16, 18, 21, 24, 25

The psychometric properties of the CDI were originally investigated by Kovacs (1981) and more recently by Fundudis and colleagues (Fundudis, Berney, Kolvin, Famuyiwa, Barrett, Bhate, & Tyrer, 1991). Internal consistency of the CDI revealed split-half reliability 0.86 (Kovaks, 1981) and 0.88 (Fundudis et al, 1991). Reliability

was estimated as 0.92, test-retest reliability coefficient of 0.71 over four weeks, as well as a moderate concurrent validity of 0.85 (Fundudis et al, 1991).

1.4.7 Childhood Behaviour Checklist (CBCL)

The Childhood Behaviour Checklist (Achenbach & Edelbrock, 1983) has been extensively used for research purposes. The CBCL is a 113 item scale for completion by parents, which assesses the severity of their child's behavioural problems. Parents are instructed:-

“Below is a list of items that describe children. For each item that describes your child **now or in the past 6 months**, please circle the 2 if the item is very true or often true of your child. If the item is not true of your child, please circle the 0. Please answer all the questions as well as you can, even if some do not seem to apply to your child.”

The items require the parent to rate how true, from 0= Not true, 1= Sometimes true, 2= Very true, certain statements about common childhood problems are for their child, for example “Demands a lot of attention”. The scores on each item are then added to create the nine subscales of withdrawn, somatic complaints, anxious/ depressed, social problems, thought problems, attention problems, delinquent behaviour, aggressive behaviour, and other problems. Further analysis can yield total scores for internalising problems (a combination of the withdrawn, somatic complaints, and anxious/ depressed subscales, minus item 103 “Unhappy, sad, depressed”) and externalising problems (derived from the delinquent behaviour and aggressive behaviour subscales). Examples of the items in each subgroup are listed below.

Withdrawn:-	Refuses to talk
Somatic complaints:-	Feels dizzy
Anxious/ depressed:-	Complains of loneliness
Social problems:-	Not liked by other children
Thought problems:-	Stares blankly
Attention problems:-	Confused or in a fog
Delinquent behaviour:-	Hangs around with children who get into trouble
Aggressive behaviour:-	Gets in many fights
Other problems:-	Fears going to school

The 113 items divided up in the following way to create the above subscales:-

Withdrawn:-	42, 65, 69, 75, 80, 88, 102, 103, 111
Somatic complaints:-	51, 54, 56a, 56b, 56c, 56d, 56e, 56f, 56g
Anxious/ depressed:-	12, 14, 31, 32, 33, 34, 35, 45, 50, 52, 71, 89, 103, 112
Social problems:-	1, 11, 25, 38, 48, 55, 62, 64
Thought problems:-	9, 40, 66, 70, 80, 84, 85
Attention problems:-	1, 8, 10, 13, 17, 41, 45, 46, 61, 62, 80
Delinquent behaviour:-	26, 39, 43, 63, 67, 72, 81, 82, 90, 96, 101, 105, 106
Aggressive behaviour:-	3, 7, 16, 19, 20, 21, 22, 23, 27, 37, 57, 68, 74, 86, 87, 93, 94, 95, 97, 104
Other problems:-	5, 6, 15, 18, 24, 28, 29, 30, 36, 44, 47, 49, 53, 56h, 58, 59, 60, 73, 76, 77, 78, 79, 83, 91, 92, 98, 99, 100, 107, 108, 109, 110, 113

The CBCL has been standardised on 1,300 non-institutionalised children. The standardisation study established good validity and a test-retest reliability of 0.82 to 0.90, depending on the age and sex of the subgroup tested.

2.5 Analysis

In order to preserve confidentiality, each child was assigned an identification number for the purposes of the remainder of the study. Following this, all other identifying factors, such as the child's name, were removed from the questionnaire responses.

Initial coding was performed by hand. Data was scored in a unidimensional basis, in other words each item on a measure was scored in the same direction regardless of the reversal of items typically used in self-report questionnaires (see description of measures in section 2.4).

Scores were then transferred onto computer data file. The data was analysed using the Statistical Package for the Social Sciences (SPSS). Syntax files were designed to re-score all items according to manual specifications, including all item reversal and calculation of subtest scores. This reduced the potential for manual data entry error. Further checks for accuracy were made by running frequencies for variables, as well as a random 10% sample being hand scored and compared with computer scoring criteria.

Data analysis involved Pearson's correlation coefficients, as well as multiple regression analysis. For the purposes of this study a minimum significance value was set at $p = 0.05$.

3 Results

3.1 Introduction

Prior to hypothesis testing, section 3.2 will initially provide a description of the subjects who took part in the study. This will include numbers and categories of the children, as well as a simple description of the nature of pain report, use of coping strategies and health locus of control beliefs.

Section 3.3 describes the process by which subscales of the various measures were selected for inclusion as criterion (dependent) variables in final analysis, whilst Section 3.4 uses these selected subscales to compare the sample of children in this research to published normative data.

Finally, section 3.5 through 3.8 describe the investigation of hypotheses and the evidence supporting their validity is described. Section 3.9, details the contribution made by the 10 separate coping strategies in explaining the variance in criterion variables.

3.2 Subjects

3.2.1 Numbers

A total of 30 children and parents agreed to take part in the study. Of the participant group 19 children were female (63.3%) and 11 were male (36.7%). The age of the children ranged from seven to 15 years of age, with a mean of 10.53 years, standard deviation 2.22 years. Whilst it was the aim to survey children of all ages from 7 to fifteen, it is of note that no children of 8 years were assessed. In addition, there were no boys aged 12, 14 and 15 years and only one girl in the 14 year old and 15 year old ranges.

3.2.2 Pain report

On average children reported that they were in little current pain, with their mean scores on the visual analogue scale being 1.13 cm from the “No pain” anchor (Std Dev= 1.42). Further analysis shows that boys reported their current pain at 1.05 cm (Std Dev= 1.50) and girls 1.18 (Std Dev= 1.18). The whole sample mean for worst pain was 5.04 (Std Dev= 3.25) with boys rating worst pain at 6.17 (Std Dev= 3.46) and girls 4.38 (Std Dev= 3.03). These figures, when compared with clinical experience of children referred in acute pain episodes, represent a relatively low report of worst pain.

3.2.3 Coping

In terms of coping strategies, the whole sample mean use of positive/ approach coping strategies was 2.70 out of a possible range of 0 to 4, with a standard deviation of 2.70. The corresponding mean for boys was 2.91 (Std Dev= 0.83) and for girls 2.58 (Std Dev= 1.30). Use of negative/ avoidance strategies for the whole sample was 2.10 (Std Dev= 0.71), with boys scoring 1.91 (Std Dev= 0.83) and girls scoring 2.21 (Std Dev= 0.63). This evidence suggests that the use of positive/ approach coping strategies was slightly more common for these children. On average the sample used a mean number of 5.37 coping strategies out of a possible 10, with a standard deviation of 1.50. Boys used an average of 5.55 coping strategies (Std Dev= 1.37), whilst girls reported using a mean number of 5.26 strategies (Std Dev= 1.59).

3.2.4 Health locus of control

Based on the data provided by Parcel and Meyers' study of 140 children (1978), children's scores on the health locus of control scales can be compared with a normative sample. The results of this analysis are summarised in Table 1. The normative data provide mean scores and standard deviations for the unidimensional scale for age ranges of 8 to 9 years, 10 to 11 years, and 11 to 12 years. As scores

increase, so does the strength of the child’s internal beliefs. Children aged 7 years, of whom there were 5 (17%), were compared to the norms for 8 year olds as age norms for this group were not reported by Parcel and Meyer (1978). In addition, 13, 14 and 15 year olds were compared with norms for 12 year olds.

Table 1: Comparison of means for unidimensional health locus of control, present study against published normative data (Parcel & Meyer, 1978).

Age	Present study		Parcel & Meyer (1978)		Difference Std Dev ♦
	Mean	Std Dev	Mean	Std Dev	
7 years*	8.00	0.71	9.99	3.73	-0.54
8 years	-	-	9.99	3.73	-
9 years	11.60	3.71	9.99	3.73	+0.43
10 years	13.75	1.26	10.98	4.19	+0.66
11 years	13.00	1.58	12.16	3.50	+0.24
12 years	12.60	3.58	12.16	3.50	+0.13
13 years***	14.50	0.58	12.16	3.50	+0.67
14 years***	17.00**	0.00	12.16	3.50	+1.39
15 years***	16.00**	0.00	12.16	3.50	+1.10

♦ This figure is expressed as the number of standard deviations the present mean deviates from normative data means, using normative standard deviation values.

* Compared to normative data for 8 to 9 year olds

** Only one subject in age range

*** Compared to normative data for 11 to 12 year olds

The mean unidimensional score for children aged 7 years in this study, is 8.00 (Std Dev= 0.71) and is 0.5 standard deviations below the mean. This is to be anticipated as internality is often reported to increase with age (see introduction). However, the mean scores for this study appear to be within 1 standard deviation of the age related mean scores, and with the exception of 7 year olds reported above, these scores differ in the direction of increased internality. It appears that the children studied in this research have similar locus of control beliefs to an external study of healthy children. It must be noted that for 13, 14 and 15 year olds, the observed differences are likely

to be inflated. This is related to the proposed increase of internal health locus beliefs with age (see introduction).

3.3 The selection of subscales for use as criterion (dependent) measures

Correlation matrices were utilised to compare the performance of the total scores for each measure with the individual subscales, in order to ascertain whether these broader scores were appropriate for hypothesis testing analysis. One of the reasons for this exercise was to help choose variables for subsequent multiple regression analysis, thus alleviating methodological difficulties associated with sample size and multicollinearity issues associated with multiple regression.

3.3.1 Revised Children’s Manifest Anxiety Scale (RCMAS)

For the Revised Children’s Manifest Anxiety Scale (RCMAS), the total anxiety scale was compared with the physiological, worry/ oversensitivity, and social concerns/ concentration subscale. The coefficients are summarised in Table 2.

Table 2: Correlation matrix for the total anxiety scale of the RCMAS with other anxiety subscales.

<u>Total anxiety</u>	r coefficient	Number of cases	Probability
Physiological	0.789	30	<0.001
Worry/ oversensitivity	0.920	30	<0.001
Social concerns/ concentration	0.822	30	<0.001

Results of subtest comparison show that the total anxiety score is significantly related to the values achieved in the other subscales. The probability values are all significant (Pearson’s $r = 0.789-0.920$, $N = 30$, $p < 0.001$). Thus it was felt that the total anxiety scale could be used to reflect the other subscales.

3.3.2 Self-Perception Scale for Children (SPPC)

The global self-worth scale on the Self-Perception Scale for Children (SPPC) was compared with the other subtests of social acceptance, physical attractiveness, scholastic, athletic competence, and behaviour. The coefficient correlation values are reported in Table 3.

Table 3: Correlation matrix for the global self-worth subscale of the SPPC with other self perception subscales.

<u>Global self-worth</u>	r coefficient	Number of cases	Probability
Social acceptance	0.504	29	0.005
Physical attractiveness	0.479	29	0.009
Scholastic	0.542	29	0.002
Athletic competence	0.285	29	0.134
Behaviour	0.444	29	0.016

As can be seen from the table, the global self worth scores correlate significantly with four of the remaining five subscales, specifically social acceptance ($r= 0.504$, $N= 29$, $p=.005$), physical attractiveness ($r= 0.479$, $N= 29$, $p=.009$), scholastic ($r= 0.542$, $N= 29$, $P= .002$), and behaviour ($r= 0.444$, $N= 29$, $p= 0.016$). Global self worth was not significantly related to athletic competence ($r= 0.285$, $N= 29$, NS). On the basis of these findings it was assumed that global self-worth could be used as the dependent variable in hypothesis testing for the SPPC.

Athletic competence itself was only significantly related to the appearance subscale ($r= 0.677$, $N= 29$, $p<.001$). This may be related to the fact that many of these children with Juvenile Chronic Arthritis are unable to participate in the complete range of physical activities available to their healthy peers.

3.3.3 Childhood Behaviour Checklist (CBCL)

The internalising and externalising subscales of the Childhood Behaviour Checklist, have been used previously in research as a measure of children's behavioural problems from parental report. This study proposed to replicate this and thus compared these two subscales against the remaining scales. The coefficients for the internalising subscale are reported in Table 4.

Table 4: Correlation matrix for the internalising subscale of the CBCL with other subscales.

<u>Internalising</u>	r coefficient	Number of cases	Probability
Withdrawal	0.847	29	<0.001
Somatic complaints	0.820	29	<0.001
Anxious/ depressed	0.928	29	<0.001
Social problems	0.776	29	<0.001
Thought problems	0.769	29	<0.001
Attention	0.843	29	<0.001
Delinquent behaviour	0.555	29	0.002
Aggressive behaviour	0.772	29	<0.001
Other problems	0.905	29	<0.001
Externalising	0.758	29	<0.001

The internalising scale seems to demonstrate an accurate reflection of the other subscales. The scale correlates with other scales significantly ($r= 0.758-0.928$, $N= 29$, $p<0.001$), with the exception of the delinquent behaviour subscale, though the relationship is still significant ($r= 0.555$, $N= 29$, $p=0.002$).

Table 5: Correlation matrix for the externalising subscale of the CBCL with other subscales.

<u>Externalising</u>	r coefficient	Number of cases	Probability
Withdrawal	0.662	29	<0.001
Somatic complaints	0.533	29	<0.001
Anxious/ depressed	0.674	29	<0.001
Social problems	0.679	29	<0.001
Thought problems	0.542	29	0.002
Attention	0.731	29	<0.001
Delinquent behaviour	0.843	29	<0.001
Aggressive behaviour	0.991	29	<0.001
Other problems	0.713	29	<0.001
Internalising	0.758	29	<0.001

Correlational coefficient analysis for the externalising subscale of the CBCL indicates that this subscale is again highly correlated with the other components of the measure. The externalising scale correlates highly with withdrawal, somatic complaints, anxious/ depressed, social problems, attention, delinquent behaviour, aggressive behaviour, other problems and the internalising scales ($r = .533-.991$, $N = 29$, $p < 0.001$), as well as with thought problems ($r = .542$, $N = 29$, $p = 0.002$).

In summary, the analysis of the subscales of the various measures indicates that the measures are closely associated internally. In order to simplify the analysis of hypotheses it is therefore proposed that the criterion (dependent) variables for ongoing analysis be current pain report, worst pain report, total anxiety, total depression, global self-worth, as well as internalising and externalising behaviour problems.

3.4 Comparison of present research group with published normative data

Having selected the above sub-scales for inclusion within this analysis, it was deemed appropriate to compare these initially with normative data which has been published for the various measures used within this research. Details of coping strategies and health locus of control beliefs have been discussed above. This section will therefore report details for the criterion (dependent) measures of total anxiety, global self worth, total depression, internalising behaviour problems, as well as externalising behaviour problems.

3.4.1 Total anxiety

Total anxiety scores for children in this study were compared with norms published by Reynolds and Richmond (1994). These norms divide children by sex into age groups, providing percentiles and T scores (mean= 50, Std Dev= 10). For the boys, the majority of mean scores were within or below acceptable limits for their age group, scoring as follows; 9 years (%ile= 17, T= 40), 10 years (%ile= 59, T= 52) and 11 years (%ile= 77, T= 58). However, mean scores of children of 7 years (%ile= 87, T= 61) and 13 years (%ile= 88, T= 62), appeared to be slightly elevated. Mean scores for girls were all below or within the average range for total anxiety scores for age peers. Specifically, 7 years (%ile= 34, T= 46), 9 years (%ile= 32, T= 45), 10 years (%ile= 15, T= 40), 11 years (%ile= 32, T= 45), 12 years (%ile= 38, T= 47), 13 years (%ile= 80, T= 58), 14 years (%ile= 57, T= 52) and 15 years (%ile= 70, T= 55).

3.4.2 Global self-worth

Global self-worth scores were compared with the normative data provided by Hoare and colleagues (Hoare, Elton, Greer, and Kerley, 1993) for ages 9 to 16. Means and standard deviation are provided for boys and girls in individual age groups. Table 6a and 6b summarise these comparisons.

Table 6a: Comparison of global self worth scores between male subjects and published norms for Lothian school children (Hoare, Elton, Greer, and Kerley, 1993).

Boys Age	Present study		Hoare and colleagues (1993)		Difference Std Dev ♦
	Mean	Std Dev	Mean	Std Dev	
7 years*	2.17	0.60	3.00	0.63	-1.30
9 years	3.17	0.24	3.00	0.63	+2.70
10 years	3.00	0.00	2.97	0.65	-0.01
11 years	3.45	0.69	3.04	0.61	+0.67
13 years	2.75	1.06	3.05	0.54	-0.52

♦ This figure is expressed as the number of standard deviations the present mean deviates from normative data means, using normative standard deviation values.

* Compared to normative data for 9 year olds

Table 6b: Comparison of global self worth scores between female subjects and published norms for Lothian school children (Hoare, Elton, Greer, and Kerley, 1993).

Girls Age	Mean	Std Dev	Mean	Std Dev	Difference Std Dev ♦
7 years*	3.16	0.00**	2.95	0.63	+0.33
9 years	3.05	0.92	2.95	0.63	+0.16
10 years	3.72	0.35	2.97	0.65	+1.15
11 years	3.92	0.12	2.92	0.63	+1.59
12 years	3.17	0.37	2.92	0.61	+0.41
13 years	2.92	1.06	2.87	0.58	+0.09
14 years	3.33	0.00**	2.82	0.53	+0.96
15 years	3.00	0.00**	2.76	0.51	+0.47

♦ This figure is expressed as the number of standard deviations the present mean deviates from normative data means, using normative standard deviation values.

* Compared to normative data for 9 year olds

** Only one subject in age range

One can see from Table 6 that the self-worth scores for boys are variable, though the only age group to score greater than one standard deviation below the age mean are 7 year olds. However, no actual mean scores are provided by Hoare and colleagues (1993) and so this result must be treated with scepticism. Of additional significance, is the finding that the 9 year old boys scored above 1 standard deviation from the mean

score for their age group. Without exception, the girls reported higher self esteem than age related peers, with the 10 and 11 year old group scoring greater than one standard deviation above the mean age norms.

3.4.3 Total depression

Depression scores for this sample were compared with the published normative data of Fundudis and colleagues (Fundudis, Berney, Kolvin, Famuyiwa, Barrett, Bhate, & Tyrer, 1991), in a study of 93 children aged from 8 to 16 years. Their whole group findings suggested a score of 15 and above on the Childhood Depression Inventory to be indicative of depression.

Mean scores for children in the present study by age group were: 7 year olds, mean= 18.25 (Std Dev= 4.57); 9 year olds, mean= 10.40 (Std Dev= 4.88); 10 year olds, mean= 9.75 (Std Dev= 6.34); 11 year olds, mean= 8.80 (Std Dev= 8.20); 12 year olds, mean= 7.60 (Std Dev= 6.07); 13 year olds, mean= 16.00 (Std Dev= 10.30); 14 year olds, mean= 11.00 (Std Dev= 0.00); 15 year olds, mean= 13.00 (Std Dev= 0.00). Whilst the majority of the sample scored below the suggested depression cut-off score, the 7 year olds and 13 year olds scored above 15. However, scores for 7 year olds should be treated with suspicion as the Fundudis study (1991) did not provide data for this age group. The mean score for 13 year olds was above the cut-off level of 15, though only by one point.

3.4.4 Internalising and externalising behaviour problems

The Childhood Behaviour Checklist (Achenbach & Edelbrock, 1983) allows scores for males and females on the internalising and externalising sub-scales, to be converted into T scores for age groups of 4 to 11 years, as well as 12 to 18 years. The manual suggests that T scores lying between 60 and 63 fall in the 'borderline' range of clinical significant problems, and T scores above this level indicate clinically significant behavioural difficulties.

As rated by their parents on the internalising scale, boys aged 7 (mean= 32.00, Std Dev= 8.49, T=80), 9 (mean= 23.00, Std Dev= 26.87, T=74), and 13 years (mean= 14.50, Std Dev= 16.26, T=65) scored above the borderline range, whilst 10 year olds (mean= 4.00, Std Dev= 0.00, T=49) and 11 year olds (mean= 7.00, Std Dev= 3.00, T=55) scored below the borderline range. Girls aged 9 years (mean= 25.00, Std Dev= 6.08, T=75) scored above the borderline range, with 13 year olds scoring in the borderline range (mean= 16.50, Std Dev= 6.36, T=63). The remaining female age groupings scored below the borderline range; 7 years, mean= 3.00, Std Dev= 4.24, T=46; 10 years, mean= 3.67, Std Dev= 2.89, T=48; 11 years, mean= 3.00, Std Dev= 1.41, T=46; 12 years, mean= 7.00, Std Dev= 3.24, T=52; 14 years, mean= 5.00, Std Dev= 0.00, T=49; and 15 years, mean= 8.00, Std Dev= 0.00, T=53.

Comparing scores on the externalising subscale for boys, identified that all of the boys were rated by their parents as falling below the borderline range; 7 years, mean= 14.50, Std Dev= 7.78, T=58; 9 years, mean= 15.00, Std Dev= 21.21, T=58; 10 years, mean= 3.00, Std Dev= 0.00, T=41; 11 years, mean= 5.33, Std Dev= 8.39, T=44; 12 years, mean= 6.50, Std Dev= 9.19, T=50. The same was true of girls aged 7 years (mean= 4.00, Std Dev= 5.66, T=44), 9 years (mean= 12.33, Std Dev= 4.04, T=57), 10 years (mean= 6.67, Std Dev= 6.03, T=50), 11 years (mean= 1.00, Std Dev= 0.00, T=37), 12 years (mean= 5.60, Std Dev= 4.88, T=51) and 14 years (mean= 2.00, Std Dev= 0.00, T=40). The only exception to this trend were girls aged 13 years, who were rated in the borderline range (mean= 12.50, Std Dev= 14.85, T=61), as well as the 15 year old girl who was rated marginally above the borderline range (mean= 17.00, Std Dev= 0.00, T=64).

3.4.5 Summary of normative comparisons

It appears that, in comparison to published normative data on age related norms, the children studied within this research report relatively good psychosocial functioning in terms of anxiety, self-esteem and depression. Anomalous scores of the 7 year old group should be interpreted with care, as there is little published normative data on this age group for these measures.

In terms of parental self-report, it has been suggested previously in this study that this may over-report children's difficulties, as parents of children with Juvenile Chronic Arthritis have been noted to over protect their children. In this way, it is perhaps less reliable to compare these reports against age related norms as they might simply reflect the nature of the disease itself. This may account for high scores on internalising scales, though it is also worth noting that parental reports of externalising behaviour problems compare favourably with age related normative data.

3.5 Hypothesis 1

Restated, the first hypothesis predicts that the use of coping strategies, as assessed by the KIDCOPE, will explain a significant proportion of the variance found in terms of reported pain and self reported health status in terms of anxiety, self-esteem, and depression, as well as parental reports of behavioural problems. Specifically this will included the following predictions:-

1(a) Positive/ approach coping strategies will be associated with lower reported pain and better perceived health status (anxiety, self-esteem, depression), as perceived by children suffering from Juvenile Chronic Arthritis.

1(b) Positive/ approach coping strategies will be associated with lower reports of behavioural maladaptation as assessed by parental report of their children.

1(c) Negative/ avoidance coping strategies will be associated with higher reported pain and poorer perceived health status, as perceived by children suffering from Juvenile Chronic Arthritis.

1(d) Negative/ avoidance coping strategies will be associated with higher reports of behavioural maladaptation as assessed by parental report of their children.

The coping style hypotheses were tested against the dependent variables of current pain report, worst pain over one week, total anxiety, global self esteem, total depression, as well as the internalising and externalising subscales of the CBCL. As hypothesised the subscale strategies of positive/ approach and negative/ avoidant were used in the analysis. Pearson's correlational analysis of the relationship between variables is summarised in Table 7.

Zero order correlational analysis revealed the following significant relationships. Current pain report was positively related to worst pain report ($r = .4937$, $N = 30$, $p = .006$), as well as total anxiety scores ($r = .4455$, $N = 30$, $p = .014$). Children's report of worst pain over the preceding week was positively related to current pain, total anxiety ($r = .4956$, $N = 30$, $p = .005$), total depression scores ($r = .5096$, $N = 29$, $p = .005$), and internalising behaviour problems ($r = .3969$, $N = 29$, $p = .033$). In addition there were trends toward significance for a positive relationship with externalising behaviour problems ($r = .3211$, $N = 29$, $p = .089$) and a negative correlation with higher global self worth ($r = -.3601$, $N = 29$, $p = .058$).

As far as coping strategies were concerned, the only significant relationship was a positive correlation between positive/ approach strategies and total anxiety scores ($r = .3623$, $N = 30$, $p = .049$).

Table 7: Correlation matrix for coping strategies and dependent variables (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Positive/ approach	Negative/ avoidance	Current pain	Worst pain	Total anxiety	Global self worth	Total depression	Internalising behaviour	Externalising behaviour
Positive/ approach	1.000 30 p= .	-.2571 30 p= .170	1.224 30 p= .519	.3020 30 p= .105	.3623 30 p= .049	.0143 29 p= .941	.2449 29 p= .200	.2120 29 p= .270	.1282 29 p= .507
Negative/ avoidance	-.2571 30 p= .170	1.000 30 p= .	.1056 30 p= .579	-.1803 30 p= .340	-.1340 30 p= .480	.1550 29 p= .422	-.1081 29 p= .577	-.1304 29 p= .500	-.1637 29 p= .396
Current pain	1.224 30 p= .519	.1056 30 p= .579	1.000 30 p= .	.4937 30 p= .006	.4455 30 p= .014	-.0436 29 p= .822	.2389 29 p= .212	.1930 29 p= .316	.2302 29 p= .230
Worst pain	.3030 30 p= .105	-.1803 30 p= .340	.4937 30 p= .006	1.000 30 p= .	.4956 30 p= .005	-.3601 29 p= .055	.5096 29 p= .005	.3969 29 p= .033	.3211 29 p= .089
Total anxiety	.3623 30 p= .049	-.1340 30 p= .480	.4455 30 p= .014	.4956 30 p= .005	1.000 30 p= .	-.5929 29 p= .001	.7708 29 p= .001	.3725 29 p= .047	.3885 29 p= .037
Global self worth	.0143 29 p= .941	.1550 29 p= .422	-.0436 29 p= .882	-.3601 29 p= .055	-.5929 29 p= .001	1.000 29 p= .	-.7248 29 p= .001	-.6317 28 p= .001	-.5769 28 p= .001
Total depression	.2449 29 p= .200	-.1081 29 p= .577	.2389 29 p= .212	.5096 29 p= .005	.7708 29 p= .001	-.7248 29 p= .001	1.000 29 p= .	.4629 28 p= .013	.5982 28 p= .001
Internalising behaviour	.2120 29 p= .270	-.1304 29 p= .500	.1930 29 p= .316	.3969 29 p= .033	.3725 29 p= .042	-.6317 28 p= .001	.4629 28 p= .013	1.000 29 p= .	.7580 29 p= .001
Externalising behaviour	.1282 29 p= .507	-.1637 29 p= .396	.2302 29 p= .230	.3211 29 p= .089	.3885 29 p= .037	-.5769 28 p= .001	.5982 28 p= .001	.7580 29 p= .	1.000 29 p= .

Total anxiety scores were related to current pain and worst pain report, positive/ approach strategies, as well negative a relationship with global self worth ($r = -.5929$, $N = 29$, $p = .001$) and positive relationships with total depression ($r = .7708$, $N = 29$, $p = <.001$), internalising behaviour problems ($r = .3725$, $N = 29$, $p = .047$) and externalising behaviour problems ($r = .3885$, $N = 29$, $p = .037$).

Global self worth scores were negatively correlated with worst pain report, total anxiety, as well as total depression ($r = -.7248$, $N = 29$, $p = <.001$), internalising behaviour problems ($r = -.6317$, $N = 29$, $p = <.001$) and externalising behaviour problems ($r = .5769$, $N = 29$, $p = .001$). In addition, total depression scores were positively related to worst pain report, total anxiety and negatively related to global self esteem. In comparison with parental self report, total depression scores were also positively correlated to internal ($r = .4629$, $N = 29$, $p = .013$) and external ($r = .5982$, $N = 29$, $p = .001$) behaviour problems.

Finally, parental reports of both internal and external behaviour problems were positively correlated with worst pain, total anxiety and total depression, as well as negatively related to global self worth. In addition, they were positively correlated between each other ($r = .7580$, $N = 29$, $p = <.001$).

Despite the disappointing relationship between coping strategy and dependent variables, multiple regressions were run for fullness of reporting. These results are presented in Table 8.

Table 8: Multiple regression analyses of the predictor variables positive/ approach and negative/ avoidant coping styles for criterion (dependent) variables of anxiety, self-esteem, depression, and behavioural problems (internal and external).

<u>Current pain</u>	<u>Multiple R</u>	<u>Cumulative Multiple R²</u>	<u>Actual R²</u>	<u>Beta</u>	<u>Sign</u>
Positive/ Approach	0.122	0.015	0.015	0.160	0.42
Negative/ avoidance	0.187	0.035	0.02	0.147	0.46
<u>Worst pain</u>					
Positive/ Approach	0.302	0.091	0.091	0.274	0.158
Negative/ Avoidance	0.320	0.102	0.011	-0.110	0.565
<u>Total anxiety</u>					
Positive/ Approach	0.362	0.131	0.131	0.351	0.069
Negative/ Avoidance	0.365	0.133	0.002	-0.044	0.815
<u>Global self-worth</u>					
Positive/ Approach	0.014	0.0002	0.0002	0.58	0.774
Negative/ Avoidance	0.165	0.027	0.0268	0.17	0.404
<u>Total depression</u>					
Positive/ Approach	0.245	0.060	0.060	0.232	0.247
Negative/ Avoidance	0.249	0.062	0.002	-0.048	0.807
<u>Internalising</u>					
Positive/ Approach	0.212	0.045	0.045	0.191	0.343
Negative/ Avoidance	0.226	0.051	0.006	-0.081	0.684
<u>Externalising</u>					
Positive/ Approach	0.128	0.016	0.016	0.092	0.647
Negative/ Avoidance	0.186	0.035	0.019	-0.140	0.489

The evidence provided does not appear to provide support for hypothesis one. Positive/ approach strategies do not explain a significant proportion of the variance in terms of current pain ($R^2 = .015$, $N = 30$, ns), worst pain ($R^2 = .091$, $N = 30$, ns), total anxiety ($R^2 = .131$, $N = 30$, ns), global self-worth ($R^2 = .0002$, $N = 29$, ns), total depression ($R^2 = .060$, $N = 29$, ns), internalising behaviour problems ($R^2 = .045$, $N = 29$, ns), externalising behaviour problems ($R^2 = .016$, $N = 29$, ns). Whilst there were no significant results, it is worth noting that in the contribution of positive approach strategies to the explanation of total anxiety, there appears to be a trend toward

significance ($R^2 = .131$, $N = 29$, $p = .069$), suggesting that as anxiety increases, so does the use of these coping strategies.

In addition, negative/ avoidance strategies did not explain a significant proportion of the variance in current pain ($R^2 = .02$, $N = 30$, ns), worst pain ($R^2 = .011$, $N = 30$, ns), total anxiety ($R^2 = .002$, $N = 30$, ns), global self-worth ($R^2 = .027$, $N = 29$, ns), total depression ($R^2 = .002$, $N = 29$, ns), internalising behaviour problems ($R^2 = .006$, $N = 29$, ns), externalising behaviour problems ($R^2 = .019$, $N = 29$, ns).

The results of analysis suggest that the coping styles of positive/ approach and negative/ avoidant do not explain a significant proportion of the variance in terms of the dependent variables. For the purposes of further analysis, it was decided to examine the contribution made to variance by the 10 coping strategies which are scored by the KIDCOPE, from which the two global coping strategies of positive/ approach and negative/ avoidance are calculated. The results from this more detailed analysis are reported below.

3.6 Hypothesis 2

As detailed in the section 1.9.3, the second hypothesis predicts that locus of control, assessed by the Children's Health Locus of Control Scale, will explain a significant proportion of the variance found in terms of reported pain and self reported health status. This study makes the following predictions about the nature of this contribution:-

2(a) Internal locus of control will be associated with lower reported pain and better perceived health status (anxiety, self-esteem, and depression) by children with Juvenile Chronic Arthritis.

2(b) Internal locus of control will be associated with lower reports of behavioural symptomatology by the parents of children with Juvenile Chronic Arthritis.

2(a) External locus of control, both chance and powerful others, will be associated with higher reported pain and worse perceived health status (anxiety, self-esteem, and depression) by children with Juvenile Chronic Arthritis.

2(b) External locus of control, both chance and powerful others, will be associated with higher reports of behavioural symptomatology by the parents of children with Juvenile Chronic Arthritis.

The locus of control hypotheses were tested against the dependent variables of current pain report, worst pain over one week, total anxiety, global self esteem, total depression, as well as the internalising and externalising subscales of the CBCL. As hypothesised the subscale strategies of internal, powerful others, and chance were used in the analysis. Zero order correlational analysis is reported in Table 9.

The relationships between criterion variables have been detailed above (see Section 3.5) and thus will not be repeated further. The only result indicating a trend toward significance is the positive relationship between powerful others locus of control and total anxiety scores ($r = .3174$, $N = 30$, $p = .087$). Internal comparisons of the subscales reveals that the powerful others locus is negatively correlated with the unidimensional scale ($r = -.9100$, $N = 29$, $p < .001$), whilst the internal and unidimensional locus scales are positively related ($r = .4935$, $N = 29$, $p = .006$).

The results of multiple regression analyses are presented in Table 10.

Table 9: Correlation matrix for health locus of control and dependent variables (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Current pain	Worst pain	Total anxiety	Global self worth	Total depression	Internal behaviour	External behaviour	Internal	Chance	Powerful	Unidimen
Current pain	1.000 30 p=	.4937 30 p=.006	.4455 30 p=.014	-.0436 29 p=.882	.2389 29 p=.212	.1930 29 p=.316	.2302 29 p=.230	.1980 30 p=.294	-.0574 30 p=.763	-.0251 30 p=.895	.1075 30 p=.572
Worst pain	.4937 30 p=.006	1.000 30 p=	.4956 30 p=.005	-.3601 29 p=.055	.5096 29 p=.005	.3969 29 p=.033	.3211 29 p=.089	-.1654 30 p=.382	-.0019 30 p=.992	.2861 30 p=.125	-.2959 30 p=.112
Total anxiety	.4455 30 p=.014	.4956 30 p=.005	1.000 30 p=	-.5929 30 p=.001	.7708 29 p<.001	.3725 29 p=.047	.3885 29 p=.037	.0995 30 p=.601	.0087 30 p=.964	.3174 30 p=.087	.2308 30 p=.220
Global self worth	-.0436 29 p=.882	-.3601 29 p=.055	-.5929 30 p=.001	1.000 29 p=	-.7248 29 p<.001	-.6317 28 p<.001	-.5769 28 p=.001	-.1671 29 p=.386	.0316 29 p=.871	-.2260 29 p=.238	.1127 29 p=.561
Total depression	.2389 29 p=.212	.5096 29 p=.005	.7708 29 p<.001	-.7248 29 p<.001	1.000 29 p=	.4629 28 p=.013	.5982 28 p=.001	-.0699 29 p=.719	-.0816 29 p=.674	.3007 29 p=.0113	-.1465 29 p=.197
Internalising behaviour	.1930 29 p=.316	.3969 29 p=.033	.3725 29 p=.047	-.5769 28 p=.055	.4629 28 p=.013	1.000 29 p=	.7580 29 p<.001	.2741 29 p=.150	.0857 29 p=.659	.2059 29 p=.284	-.1148 29 p=.553
Externalisin g behaviour	.2302 29 p=.230	.3211 29 p=.089	.3885 29 p=.037	-.5769 28 p=.001	.5982 28 p=.013	-.7580 29 p<.001	1.000 29 p=	.2382 29 p=.213	.0671 29 p=.729	.0295 29 p=.879	.0305 29 p=.875
Internal	.1980 30 p=.294	-.1654 30 p=.382	.0995 30 p=.601	-.1671 29 p=.386	-.0699 29 p=.719	.2741 29 p=.150	.2382 29 p=.213	1.000 30 p=	.1396 30 p=.462	-.2138 30 p=.256	.4935 30 p=.006
Chance	-.0574 30 p=.763	-.0019 30 p=.992	.0087 30 p=.964	.0316 29 p=.871	-.0816 29 p=.964	.0857 29 p=.659	.0671 29 p=.729	.1396 30 p=.462	1.000 30 p=	.0119 30 p=.950	-.2431 30 p=
Powerful	-.0251 30 p=.895	.2861 30 p=.125	.3174 30 p=.2308	-.2260 29 p=.561	.3007 29 p=.238	.2059 29 p=.561	.0295 29 p=.875	-.2138 30 p=.006	.0119 30 p=.950	1.000 29 p=	-.9100 30 p<.001
Unidimen	.1075 30 p=.572	-.2959 30 p=.112	-.2308 30 p=.220	.1127 29 p=.561	-.2465 29 p=.197	-.1148 29 p=.553	.0305 29 p=.875	.4935 30 p=.006	-.2431 30 p=.950	-.9100 30 p<.001	1.000 29 p=

Table 10: Multiple regression analyses for the predictor variables of internal, powerful others, and chance locus of control for the criterion (dependent) variables of anxiety, self-esteem, depression, and behavioural problems (internal and external).

<u>Current Pain</u>	<u>Multiple R</u>	<u>Cumulative Multiple R²</u>	<u>Actual Multiple R²</u>	<u>Beta</u>	<u>Sign</u>
Internal	0.198	0.039	0.039	0.215	0.288
Chance	0.216	0.047	0.008	-0.088	0.654
Powerful others	0.217	0.047	0.001	0.022	0.912
<u>Worst Pain</u>					
Internal	0.165	0.027	0.027	-0.111	0.571
Chance	0.167	0.028	0.001	0.010	0.956
Powerful others	0.306	0.093	0.065	0.262	0.182
<u>Total Anxiety</u>					
Internal	0.099	0.010	0.010	0.178	0.354
Chance	0.099	0.010	0.001	-0.020	0.913
Powerful others	0.361	0.131	0.121	0.356	0.069
<u>Global self-worth</u>					
Internal	0.167	0.028	0.028	-0.236	0.240
Chance	0.176	0.031	0.003	-0.086	0.657
Powerful others	0.323	0.104	0.073	-0.277	0.165
<u>Total depression</u>					
Internal	0.670	0.005	0.005	0.007	0.972
Chance	0.101	0.010	0.005	-0.086	0.657
Powerful others	0.313	0.098	0.088	0.303	0.132
<u>Internalising</u>					
Internal	0.274	0.075	0.075	0.328	0.098
Chance	0.278	0.077	0.002	0.037	0.846
Powerful others	0.387	0.150	0.073	0.276	0.157
<u>Externalising</u>					
Internal	0.238	0.057	0.057	0.252	0.220
Chance	0.241	0.058	0.001	0.031	0.875
Powerful others	0.254	0.064	0.006	0.952	0.679

Results obtained from the multiple regression analyses of the contribution made by health locus of control, do not appear to support the assertions of Hypothesis 2. Internal locus of control does not explain a significant proportion of the variance found in current pain ($R^2 = .039$, $N = 30$, ns), worst pain ($R^2 = .027$, $N = 30$, ns), total anxiety ($R^2 = .010$, $N = 30$, ns), global self-worth ($R^2 = .028$, $N = 29$, ns), total depression ($R^2 = .005$, $N = 29$, ns), internalising behaviour problems ($R^2 = .075$, $N = 29$, ns), externalising behaviour problems ($R^2 = .057$, $N = 29$, ns). In explaining internalising behaviours, there is a trend towards significance of internal locus of control ($R^2 = .075$, $N = 29$, $p = .098$), which suggests that there is a trend for children with a more internal locus to exhibit more internalising behaviours from parental self report.

In addition, the scales of external locus of control do not appear to explain a significant proportion of the variance in dependent variables. The contribution of powerful others with criterion measures is current pain ($R^2 = .008$, $N = 29$, ns), worst pain ($R^2 = .001$, $N = 29$, ns), total anxiety ($R^2 = .001$, $N = 29$, ns), global self-worth ($R^2 = .003$, $N = 29$, ns), total depression ($R^2 = .005$, $N = 29$, ns), internalising behaviour problems ($R^2 = .002$, $N = 29$, ns), externalising behaviour problems ($R^2 = .001$, $N = 29$, ns). Likewise, chance locus of control explains variance in current pain ($R^2 = .001$, $N = 29$, ns), worst pain ($R^2 = .065$, $N = 29$, ns), total anxiety ($R^2 = .121$, $N = 29$, ns), global self-worth ($R^2 = .013$, $N = 29$, ns), total depression ($R^2 = .088$, $N = 29$, ns), internalising behaviour problems ($R^2 = .073$, $N = 29$, ns), externalising behaviour problems ($R^2 = .006$, $N = 29$, ns). Examination of the variance in total anxiety scores indicates a trend towards significance in the powerful others scale ($R^2 = .131$, $N = 29$, $p = .069$), indicating that children who report higher levels of anxiety have a greater belief in the control of powerful others.

3.7 Hypothesis 3

The third hypothesis predicted that positive/ approach coping strategies will be associated with internal locus of control. Specifically:-

3(a) Positive/ approach coping strategies will be associated with internal locus of control.

3(b) Negative/ avoidance coping strategies will be associated with the external orientations of chance and powerful others.

Pearson's correlational analysis was used to examine these predictions and the results are summarised in Table 11.

Evidence for the relationship between positive strategies and internal health locus of control was not found, as these variables were not significantly related ($r = .081$, $N = 30$, $p = .671$). Likewise, negative/ avoidant strategies were not significantly related to chance locus ($r = -.022$, $N = 30$, $p = .909$) or powerful other locus ($r = -.045$, $N = 30$, $p = .815$). Evidence obtained from this study, suggests that the prediction of association between coping strategies and health locus of control cannot be substantiated.

Table 11: Zero order correlational matrix for coping strategies and health locus of control (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Positive/ approach	Negative/ avoidance	Internal	Chance	Powerful	Unidimensional
Positive/ approach	1.000 30 p= .	-.2571 30 p= .170	.0808 30 p= .671	.1760 30 p= .352	.0484 30 p= .800	-.0612 30 p= .748
Negative/ avoidance	-.2571 30 p= .170	1.000 30 p= .	-.0435 30 p= .820	-.0218 30 p= .909	-.0446 30 p= .815	.0278 30 p= .884
Internal	.0808 30 p= .671	-.0435 30 p= .820	1.000 30 p= .	.1396 30 p= .462	-.2138 30 p= .256	.4935 30 p= .006
Chance	.1760 30 p= .352	-.0218 30 p= .909	.1396 30 p= .462	1.000 30 p= .	.0119 30 p= .950	-.2431 30 p= .196
Powerful	.0484 30 p= .800	-.0446 30 p= .815	-.2138 30 p= .256	.0119 30 p= .950	1.000 30 p= .	-.9100 30 p< .001
Unidimensional	-.0612 30 p= .748	.0278 30 p= .884	.4935 30 p= .006	-.3431 30 p= .196	-.9100 30 p< .001	1.000 30 p= .

3.8 Hypothesis 4

The final prediction made by this research concerns the contribution that age might make to the development of coping style and health locus of control. Specifically:-

4(a) As children's age increases, more positive/ approach coping strategies will be used by children.

4(b) As age increases, children will develop a more internalised locus of control.

The results of zero order correlational analysis are presented in Table 12.

Using Pearson's correlational analysis, the evidence from this study suggested that there was no significant relationship between older children and an increasing use of positive/ approach coping strategies ($r = -.070$, $N = 30$, $p = .713$). In addition, using the multidimensional scoring for health locus of control, an increasing internal orientation was not significantly related to children's age ($r = .292$, $N = 30$, $p = .117$).

However, there was a significant relationship between age and control by powerful others ($r = -.689$, $N = 30$, $p = <.001$), suggesting that as age increases children decreasingly believe that control over their health is governed by doctors, nurses and parents. Furthermore, using the unidimensional scoring scale which gives a single measure of the internality of a child's health beliefs, there did appear to be a significant relationship between internality and age ($r = .675$, $N = 30$, $p = <.001$). This suggests that as age increases, so do children's scores on a unidimensional construct of internal health locus of control.

Table 12: Zero order correlational matrix for coping strategies and health locus of control (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Positive/ approach	Negative/ avoidance	Internal	Chance	Powerful	Unidimensional	Age
Positive/ approach	1.000 30 p=	-.2571 30 p= .170	.0808 30 p= .671	.1760 30 p= .352	.0484 30 p= .800	-.0612 30 p= .748	-.0702 30 p= .713
Negative/ avoidance	-.2571 30 p= .170	1.000 30 p=	-.0435 30 p= .820	-.0218 30 p= .909	-.0446 30 p= .815	.0278 30 p= .884	.0958 30 p= .615
Internal	.0808 30 p= .671	-.0435 30 p= .820	1.000 30 p=	.1396 30 p= .462	-.2138 30 p= .256	.4935 30 p= .006	.2922 30 p= .117
Chance	.1760 30 p= .352	-.0218 30 p= .909	.1396 30 p= .462	1.000 30 p=	.0119 30 p= .950	-.2431 30 p= .196	.0035 30 p= .985
Powerful	.0484 30 p= .800	-.0446 30 p= .815	-.2138 30 p= .256	.0119 30 p= .950	1.000 30 p=	-.9100 30 p= .001	-.6892 30 p= .001
Unidimensional	-.0612 30 p= .748	.0278 30 p= .884	.4935 30 p= .006	-.3431 30 p= .196	-.9100 30 p= .001	1.000 30 p=	.6753 30 p= .001
Age	.0702 30 p= .713	.0958 30 p= .615	.2922 30 p= .117	.0035 30 p= .985	-.6892 30 p= .001	.6753 30 p= .001	1.000 30 p=

3.9 The contribution of the 10 coping strategies to variance in criterion (dependent) measures

As previously detailed in the investigation of Hypothesis 1, it was felt that an assessment of the variance explained by the 10 individual coping strategies was warranted, since limited variance had been explained by the two broad sub-categories of coping (positive/ approach and negative/ avoidance).

Pearson's two tailed correlations are presented in Table 13 for the individual coping strategies. A cursory look at the structure of the items which make up the positive/ approach and negative/ avoidance scales indicates that these factors, according to this study, do not appear to be significantly related. For example, on the positive/ approach scale, cognitive restructuring is not significantly correlated with the other measures of problem solving ($r = -.098$, $N = 30$, ns), emotional regulation ($r = .3424$, $N = 30$, ns) and social support ($r = .112$, $N = 30$, ns). The same is true of the negative/ avoidance scale with, for example, distraction unrelated to blaming others ($r = .175$, $N = 30$, ns), wishful thinking ($r = -.200$, $N = 30$, ns) and resignation ($r = .098$, $N = 30$, ns). In fact the only expected significant correlation between these subscales is between problem solving and social support ($r = .398$, $N = 30$, $p = .029$). Whilst this is only a very basic examination of the subscales, it nevertheless casts some doubt as to the internal relationships observed herein and may explain the disappointing results obtained in examination of hypothesis 1 above.

3.9.1 Current pain report

Initial analysis of the relationship between current pain report was made using Pearson's correlational analysis. These are presented in Table 13.

Table 13: Zero order correlational matrix for the 10 individual coping strategies and current pain report (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Current pain	Distraction	Social withdrawal	Cognitive restruct'g	Self criticism	Blame	Problem solving	Emotional regulation	Wishful thinking	Social support	Resignat'n
Current pain	1.000 30 p=	-.0085 30 p=.964	.2966 30 p=.111	.2444 30 p=.193	.0488 30 p=.798	-.2548 30 p=.174	-.1451 30 p=.444	.1962 30 p=.299	.0874 30 p=.646	-.0038 30 p=.984	.2861 30 p=.125
Distraction	-.0085 30 p=.964	1.000 30 p=	.1265 30 p=.505	-.1265 30 p=.505	.2467 30 p=.189	.1754 30 p=.254	-.1547 30 p=.414	-.3403 30 p=.066	-.2000 30 p=.289	.1762 30 p=.352	.0976 30 p=.608
Social withdrawal	.2966 30 p=.111	.1265 30 p=.505	1.000 30 p=	-.1000 30 p=.599	.2786 30 p=.136	.3467 30 p=.061	-.1956 30 p=.300	.0978 30 p=.607	.1265 30 p=.505	-.1115 30 p=.558	-.1543 30 p=.416
Cognitive restructuring	.2444 30 p=.193	-.1265 30 p=.505	.1265 30 p=.505	1.000 30 p=	.2229 30 p=.236	-.1387 30 p=.465	-.0978 30 p=.607	.3424 30 p=.064	.02530 30 p=.177	.1115 30 p=.558	.0000 30 p=.1000
Self criticism	.0488 30 p=.798	-.2548 30 p=.174	.2966 30 p=.111	.2444 30 p=.193	.0488 30 p=.798	-.2548 30 p=.174	-.1451 30 p=.444	.1962 30 p=.299	.0874 30 p=.646	-.0038 30 p=.984	.2861 30 p=.125
Blame	-.2548 30 p=.174	.1754 30 p=.254	.1265 30 p=.505	-.1265 30 p=.505	.2467 30 p=.189	.3467 30 p=.061	-.1547 30 p=.414	-.3403 30 p=.066	-.2000 30 p=.289	.1762 30 p=.352	.0976 30 p=.608
Problem solving	.1451 30 p=.444	-.1547 30 p=.414	-.1956 30 p=.300	-.0978 30 p=.607	.0927 30 p=.188	.0950 30 p=.618	1.000 30 p=	.2823 30 p=.131	.0309 30 p=.871	.3980 30 p=.029	-.4076 30 p=.025
Emotional regulation	.1962 30 p=.299	-.3403 30 p=.066	.0978 30 p=.607	.3424 30 p=.064	-.2562 30 p=.172	-.1085 30 p=.568	.2823 30 p=.131	1.000 30 p=	.0309 30 p=.871	-.0927 30 p=.626	.0453 30 p=.812
Wishful thinking	.0874 30 p=.646	-.2000 30 p=.289	.1265 30 p=.505	.2530 30 p=.177	.0352 30 p=.853	-.0877 30 p=.645	.0309 30 p=.871	.0309 30 p=.871	1.000 30 p=	-.0352 30 p=.853	-.0976 30 p=.608
Social support	-.0038 30 p=.984	.1762 30 p=.352	-.1115 30 p=.558	.1115 30 p=.558	.1180 30 p=.535	-.0155 30 p=.935	.3980 30 p=.025	-.0352 30 p=.812	1.000 30 p=	-.3268 30 p=.078	-.3268 30 p=.078
Resignation	.2861 30 p=.572	.0976 30 p=.608	-.1543 30 p=.416	.0000 30 p=.1000	-.3612 30 p=.050	-.2568 30 p=.171	-.4076 30 p=.025	.0453 30 p=.812	-.0976 30 p=.608	-.3268 30 p=.078	1.000 30 p=

The zero order correlations revealed that the only variables which might contribute substantially to the variance in current pain report are social withdrawal ($r = .2966$, $N = 30$, $p = .111$) and resignation ($r = .2861$, $N = 30$, $p = .125$). These variables which were approaching significance were entered into the subsequent multiple regression analysis. The multiple regression analysis of these coping strategies for current pain report is reported in Table 14.

Table 14: Multiple regression analysis of the 10 individual coping strategies (predictor variables) for the dependent variable of current pain report.

<u>Current Pain</u>	<u>Multiple R</u>	<u>Cumulative Multiple R²</u>	<u>Actual Multiple R²</u>	<u>Beta</u>	<u>Sign</u>
Social withdrawal	.297	.088	.088	.349	.055
Resignation	.448	.201	.113	.340	.061

Analysis of the variance in current pain report made by the coping strategies reveals that both the strategies entered into the multiple regression equation explain a proportion of the variance approaching significance, social withdrawal ($R^2 = .088$, $N = 30$, $p = .055$) and resignation ($R^2 = .113$, $N = 30$, $p = .061$). This suggests that increasing use of social withdrawal and resignation is associated with greater report of current pain status.

3.9.2 Worst Pain Report

The zero order correlations between worst pain report and the 10 coping strategies is summarised in Table 15.

Results of the correlational analysis suggests that the most promising candidates for explaining variance in worst pain report appear to be social withdrawal ($r = .3580$, $N = 30$, $p = .052$) and problem solving ($r = .3510$, $N = 30$, $p = .057$). The multiple regression analysis for these variables, which were approaching significance, is presented in Table 16.

Table 15: Zero order correlational matrix for the 10 individual coping strategies and worst pain report (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Worst pain	Distraction	Social withdrawal	Cognitive restruct'g	Self criticism	Blame	Problem solving	Emotional regulation	Wishful thinking	Social support	Resignat'n
Worst pain	1.000 30 p= .	-.2571 30 p= .170	.3580 30 p= .052	.0221 30 p= .908	-.0389 30 p= .838	.1299 30 p= .494	.3510 30 p= .057	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193
Distraction	-.2571 30 p= .170	1.000 30 p= .	.1265 30 p= .505	-.1265 30 p= .505	.2467 30 p= .189	.1754 30 p= .254	-.1547 30 p= .414	-.3403 30 p= .066	-.2000 30 p= .289	.1762 30 p= .352	.0976 30 p= .608
Social withdrawal	.3580 30 p= .052	.1265 30 p= .505	1.000 30 p= .	-.1000 30 p= .599	.2786 30 p= .136	.3467 30 p= .061	-.1956 30 p= .300	.0978 30 p= .607	.1265 30 p= .505	-.1115 30 p= .558	-.1543 30 p= .416
Cognitive restructuring	.0221 30 p= .908	-.1265 30 p= .505	-.1000 30 p= .599	1.000 30 p= .	.2229 30 p= .236	-.1387 30 p= .465	-.0978 30 p= .607	.3424 30 p= .064	.02530 30 p= .177	.1115 30 p= .558	.0000 30 p= 1.000
Self criticism	-.0389 30 p= .838	.1299 30 p= .494	.3510 30 p= .057	-.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193
Blame	.1299 30 p= .494	.3510 30 p= .057	-.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117
Problem solving	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798
Emotional regulation	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597
Wishful thinking	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117
Social support	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597
Resignation	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798	-.2446 30 p= .193	.1927 30 p= .117	.1006 30 p= .597	.0488 30 p= .798

Table 16: Multiple regression analysis of the social withdrawal and problem solving coping strategies (predictor variables) for the dependent variable of worst pain report.

<u>Worst Pain</u>	<u>Multiple R</u>	<u>Cumulative Multiple R²</u>	<u>Actual Multiple R²</u>	<u>Beta</u>	<u>Sign</u>
Social withdrawal	.358	.128	.128	.444	.011
Problem solving	.559	.312	.184	.438	.012

Multiple regression analysis reveals that the these predictor variables explain a significant proportion of the variance in children's self- report of worst pain over the previous week. Specifically, social withdrawal ($R^2 = .128$, $N = 30$, $p = .011$) and problem solving ($R^2 = .184$, $N = 30$, $p = .012$). These results suggest that as children report increased pain, they appear to use more social withdrawal and problem solving strategies.

3.9.3 Total anxiety

Pearson's correlations for this criterion variable are summarised in Table 17.

The correlation coefficients reported in Table 17 indicate that the variables most likely to explain a significant proportion of the variance in total anxiety scores appear to be distraction ($r = -.3051$, $N = 30$, $p = .101$), social withdrawal ($r = .3819$, $N = 30$, $p = .037$), and social support ($r = .3831$, $N = 30$, $p = .037$). The multiple regression analysis for the variance in total anxiety explained by these coping strategies, which were significant or approaching significance, is summarised in Table 18.

Table 17: Zero order correlational matrix for the 10 individual coping strategies and total anxiety (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Total anxiety	Distraction	Social withdrawal	Cognitive restructuring	Self criticism	Blame	Problem solving	Emotional regulation	Wishful thinking	Social support	Resignation
Total anxiety	1.000 30 p=	-.3051 30 p=.101	.3819 30 p=.037	.1105 30 p=.561	-.0918 30 p=.629	-.1310 30 p=.490	.2222 30 p=.238	.1829 30 p=.333	.2670 30 p=.154	.3821 30 p=.037	-.0765 30 p=.688
Distraction	-.3051 30 p=.101	1.000 30 p=	.1265 30 p=.505	-.1265 30 p=.505	.2467 30 p=.189	.1754 30 p=.254	-.1547 30 p=.414	-.3403 30 p=.066	-.2000 30 p=.289	.1762 30 p=.352	.0976 30 p=.608
Social withdrawal	.3819 30 p=.037	.1265 30 p=.505	1.000 30 p=	-.1000 30 p=.599	.2786 30 p=.136	.3467 30 p=.061	-.1956 30 p=.300	.0978 30 p=.607	.1265 30 p=.505	-.1115 30 p=.558	-.1543 30 p=.416
Cognitive restructuring	.1105 30 p=.561	-.1265 30 p=.505	-.1000 30 p=.599	1.000 30 p=	.2229 30 p=.236	-.1387 30 p=.465	-.0978 30 p=.607	.3424 30 p=.064	.02530 30 p=.177	.1115 30 p=.558	.0000 30 p=1.000
Self criticism	-.0918 30 p=.629	.2467 30 p=.189	.2786 30 p=.136	.2229 30 p=.236	1.000 30 p=	.2473 30 p=.188	.0927 30 p=.626	.2562 30 p=.172	.0352 30 p=.853	.1180 30 p=.535	-.3612 30 p=.050
Blame	-.1310 30 p=.490	.1754 30 p=.254	.3467 30 p=.061	-.1387 30 p=.465	.2473 30 p=.188	1.000 30 p=	.0950 30 p=.618	-.1085 30 p=.568	-.0877 30 p=.645	-.0155 30 p=.935	-.2568 30 p=.171
Problem solving	.2222 30 p=.238	-.1547 30 p=.414	-.1956 30 p=.300	-.0978 30 p=.607	.3424 30 p=.064	.02530 30 p=.177	1.000 30 p=	.2823 30 p=.131	.0309 30 p=.871	.3980 30 p=.029	-.4076 30 p=.025
Emotional regulation	.1829 30 p=.333	-.3403 30 p=.066	.0978 30 p=.607	.3424 30 p=.064	-.0927 30 p=.626	-.1085 30 p=.568	.2823 30 p=.131	1.000 30 p=	.0309 30 p=.871	-.0927 30 p=.626	.0453 30 p=.812
Wishful thinking	.2670 30 p=.154	.2000 30 p=.289	.1000 30 p=.505	.2530 30 p=.177	.0352 30 p=.853	-.0877 30 p=.645	.0309 30 p=.871	.0309 30 p=.871	1.000 30 p=	-.0352 30 p=.853	-.0976 30 p=.608
Social support	.3821 30 p=.037	.1762 30 p=.352	-.1115 30 p=.558	.1115 30 p=.558	.1180 30 p=.535	-.0155 30 p=.935	.3980 30 p=.029	-.0352 30 p=.853	-.0352 30 p=.853	1.000 30 p=	-.3268 30 p=.078
Resignation	-.0765 30 p=.688	.0976 30 p=.608	-.1543 30 p=.416	.0000 30 p=1.000	-.3612 30 p=.050	-.2568 30 p=.171	-.4076 30 p=.025	.0453 30 p=.812	-.0976 30 p=.608	-.3268 30 p=.078	1.000 30 p=

Table 18: Multiple regression analysis of the 10 individual coping strategies (predictor variables) for the dependent variable of total anxiety.

<u>Total anxiety</u>	<u>Multiple R</u>	<u>Cumulative Multiple R²</u>	<u>Actual Multiple R²</u>	<u>Beta</u>	<u>Sign</u>
Distraction	.305	.093	.093	-.460	.0026
Social withdrawal	.522	.273	.180	.498	.0012
Social support	.728	.529	.256	.520	.0009

Investigation of the variance in children's self-reports of total anxiety reveals that a significant proportion of this variance is explained by the variables of distraction ($R^2 = .093$, $N = 30$, $p = .0026$), social withdrawal ($R^2 = .180$, $N = 30$, $p = .0012$) and social support ($R^2 = .256$, $N = 30$, $p = .0009$). It appears that as anxiety scores increase, children report the use of less distraction, as well as more social withdrawal and social support.

3.9.4 Global self-worth

Initial zero order correlations for global self worth are presented in Table 19.

The only predictor variables which are, or appear to be approaching, significant are those of social withdrawal ($r = -.4656$, $N = 29$, $p = .011$) and resignation ($r = .2962$, $N = 29$, $p = .119$). These factors, which were significant or approaching significance, were chosen for multiple regression analysis. The analysis of the variance accounted for by these variables in global self-esteem is summarised in Table 20.

Table 19: Zero order correlational matrix for the 10 individual coping strategies and global self-worth (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Global self-worth	Distraction	Social withdrawal	Cognitive restruct'g	Self criticism	Blame	Problem solving	Emotional regulation	Wishful thinking	Social support	Resignat'n
Global self-worth	1.000 29 p=.	.1665 29 p=.388	-.4656 29 p=.011	.1228 29 p=.526	-.1193 29 p=.538	-.2124 29 p=.269	-.0505 29 p=.795	.0051 29 p=.979	-.0434 29 p=.823	-.0454 29 p=.815	.2962 29 p=.119
Distraction	.1665 29 p=.388	1.000 30 p=.	.1265 30 p=.505	-.1265 30 p=.505	.2467 30 p=.189	.1754 30 p=.254	-.1547 30 p=.414	-.3403 30 p=.066	-.2000 30 p=.289	.1762 30 p=.352	.0976 30 p=.608
Social withdrawal	-.4656 29 p=.011	.1265 30 p=.505	1.000 30 p=.	-.1000 30 p=.599	.2786 30 p=.136	.3467 30 p=.061	-.1956 30 p=.300	.0978 30 p=.607	.1265 30 p=.505	-.1115 30 p=.558	-.1543 30 p=.416
Cognitive restructuring	.1228 29 p=.526	-.1265 30 p=.505	-.1000 30 p=.599	1.000 30 p=.	.2229 30 p=.236	-.1387 30 p=.465	-.0978 30 p=.607	.3424 30 p=.064	.02530 30 p=.177	.1115 30 p=.558	.0000 30 p=1.000
Self criticism	-.1193 29 p=.538	.2467 30 p=.189	.2786 30 p=.136	.2229 30 p=.236	1.000 30 p=.	.2473 30 p=.188	.0927 30 p=.618	.2562 30 p=.568	.0352 30 p=.645	.1180 30 p=.935	-.3612 30 p=.171
Blame	.2124 29 p=.269	-.1547 30 p=.414	-.1956 30 p=.505	-.0978 30 p=.607	.0927 30 p=.568	.0950 30 p=.618	1.000 30 p=.1000	.2823 30 p=.131	.0309 30 p=.871	.3980 30 p=.029	-.4076 30 p=.025
Problem solving	-.0505 29 p=.795	.0505 30 p=.131	.0950 30 p=.618	.0927 30 p=.568	.0950 30 p=.618	.0950 30 p=.618	1.000 30 p=.1000	.2823 30 p=.131	.0309 30 p=.871	.3980 30 p=.029	-.4076 30 p=.025
Emotional regulation	.0051 29 p=.979	-.0434 29 p=.823	-.0454 29 p=.815	.0051 29 p=.979	.0051 29 p=.979	.0051 29 p=.979	.0051 29 p=.979	.0051 29 p=.979	.0051 29 p=.979	.0051 29 p=.979	.0051 29 p=.979
Wishful thinking	-.0434 29 p=.823	-.0454 29 p=.815	-.0454 29 p=.815	-.0434 29 p=.823	-.0434 29 p=.823	-.0434 29 p=.823	-.0434 29 p=.823	-.0434 29 p=.823	-.0434 29 p=.823	-.0434 29 p=.823	-.0434 29 p=.823
Social support	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815	-.0454 29 p=.815
Resignation	.2962 29 p=.119	.0976 30 p=.608	-.1543 30 p=.416	.0000 30 p=1.000	-.3612 30 p=.050	-.2568 30 p=.171	-.4076 30 p=.025	.0453 30 p=.812	-.0976 30 p=.608	-.3268 30 p=.078	1.000 30 p=.

Table 20: Multiple regression analysis of social withdrawal and resignation (predictor variables) for the dependent variable of global self-esteem.

<u>Global self-esteem</u>	<u>Multiple R</u>	<u>Cumulative Multiple R²</u>	<u>Actual Multiple R²</u>	<u>Beta</u>	<u>Sign</u>
Social withdrawal	.466	.217	.217	-.430	.018
Resignation	.518	.268	.051	.230	.188

In explaining the variance in global self-esteem the only strategy that appears to explain a significant proportion of the variance in global self-esteem is that of social withdrawal ($R^2 = .217$, $N = 29$, $p = .018$). This suggests that as global self-esteem improves, children seem to use the strategy of social withdrawal less.

3.9.5 Total depression

Zero order correlational coefficients for the 10 coping strategies and total depression scores are presented in Table 21.

The results suggest that the coping strategies of distraction ($r = -.3197$, $N = 29$, $p = .091$) and social withdrawal ($r = .4848$, $N = 29$, $p = .008$) are most likely to explain a significant proportion of the variance in total depression. Multiple regression analysis of the dependent variable of total depression with these predictor variables is reported in Table 22.

Table 21: Zero order correlational matrix for the 10 individual coping strategies and total depression (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Total depression	Distraction	Social withdrawal	Cognitive restruct'g	Self criticism	Blame	Problem solving	Emotional regulation	Wishful thinking	Social support	Resignat'n
Total depression	1.000 29 p=.	-.3197 29 p=.091	.4848 29 p=.008	.0498 29 p=.198	-.0765 29 p=.693	.0707 29 p=.715	.2099 29 p=.274	.0955 29 p=.622	.2696 29 p=.157	.2384 29 p=.213	-.1781 29 p=.355
Distraction	-.3197 29 p=.091	1.000 30 p=.	.1265 30 p=.505	-.1265 30 p=.505	.2467 30 p=.189	.1754 30 p=.254	-.1547 30 p=.414	-.3403 30 p=.066	-.2000 30 p=.289	.1762 30 p=.352	.0976 30 p=.608
Social withdrawal	.4848 29 p=.008	.1265 30 p=.505	1.000 30 p=.	-.1000 30 p=.599	.2786 30 p=.136	.3467 30 p=.061	-.1956 30 p=.300	.0978 30 p=.607	.1265 30 p=.505	-.1115 30 p=.558	-.1543 30 p=.416
Cognitive restructuring	.0498 29 p=.198	-.1265 30 p=.505	-.1000 30 p=.599	1.000 30 p=.	.2229 30 p=.236	-.1387 30 p=.465	-.0978 30 p=.607	.3424 30 p=.064	.02530 30 p=.177	.1115 30 p=.558	.0000 30 p=.1.000
Self criticism	-.0765 29 p=.693	.2467 30 p=.189	.2786 30 p=.136	.2229 30 p=.	1.000 30 p=.	.2473 30 p=.188	.0927 30 p=.626	.2562 30 p=.172	.0352 30 p=.853	.1180 30 p=.535	-.3612 30 p=.050
Blame	.0707 29 p=.715	.1754 30 p=.254	.3467 30 p=.061	-.1387 30 p=.465	.2473 30 p=.188	1.000 30 p=.	.0950 30 p=.618	-.1085 30 p=.568	-.0877 30 p=.645	-.0155 30 p=.935	-.2568 30 p=.171
Problem solving	.2099 29 p=.274	-.1547 30 p=.414	-.1956 30 p=.300	-.0978 30 p=.607	.0927 30 p=.626	.0950 30 p=.618	1.000 30 p=.	.2823 30 p=.131	.0309 30 p=.871	.3980 30 p=.029	-.4076 30 p=.025
Emotional regulation	.0955 29 p=.622	-.3403 30 p=.066	.3424 30 p=.607	.3424 30 p=.064	-.2562 30 p=.172	-.1085 30 p=.568	.2823 30 p=.131	1.000 30 p=.	.0309 30 p=.871	-.0927 30 p=.626	.0453 30 p=.812
Wishful thinking	.2696 29 p=.157	-.2000 30 p=.289	.1265 30 p=.505	.2530 30 p=.177	.0352 30 p=.853	-.0877 30 p=.645	.0309 30 p=.871	.0309 30 p=.871	1.000 30 p=.	-.0352 30 p=.853	-.0976 30 p=.608
Social support	.2384 29 p=.213	.1762 30 p=.352	-.1115 30 p=.558	.1115 30 p=.558	.1180 30 p=.535	-.0155 30 p=.935	.3980 30 p=.029	-.0927 30 p=.025	.0309 30 p=.871	1.000 30 p=.	-.3268 30 p=.078
Resignation	-.1781 29 p=.355	.0976 30 p=.608	-.1543 30 p=.416	.0000 30 p=.1.000	-.3612 30 p=.050	-.2568 30 p=.171	-.4076 30 p=.025	.0453 30 p=.812	-.0976 30 p=.608	-.3268 30 p=.078	1.000 30 p=.

Table 22: Multiple regression analysis of distraction and social withdrawal (predictor variables) for the dependent variable of total depression.

<u>Total depression</u>	<u>Multiple R</u>	<u>Cumulative Multiple R²</u>	<u>Actual Multiple R²</u>	<u>Beta</u>	<u>Sign</u>
Distraction	.320	.102	.102	-.387	.019
Social withdrawal	.619	.383	.281	.534	.002

The variance in terms of total depression scores, appears to be explained to a significant level by the variables of distraction ($R^2 = .102$, $N = 29$, $p = .019$) and social withdrawal ($R^2 = .281$, $N = 29$, $p = .002$). it appears that, as children's self reported depression scores increase, they use less distraction and more social withdrawal.

3.9.6 Behavioural problems

Correlational coefficients for coping strategies and internalising behaviour problems are summarised in Table 23 and externalising behaviour problems in Table 24.

As can be seen from the tables, there does not appear to be any significant relationship between parental report of behaviour problems and use of coping strategies reported by children. For these criterion variables no further analysis was attempted.

Table 23: Zero order correlational matrix for the 10 individual coping strategies and internalising behaviour problems (Pearson's r coefficient/ Cases/ 2-tailed significance)

	Internalis' g	Distraction	Social withdrawal	Cognitive restruct' g	Self criticism	Blame	Problem solving	Emotional regulation	Wishful thinking	Social support	Resignat' n
Internalising	1.000 29 p=.	.0574 29 p=.767	.0759 29 p=.696	.1935 29 p=.315	.0725 29 p=.709	-.0148 29 p=.939	.1009 29 p=.603	-.0622 29 p=.749	.0253 29 p=.897	.3111 29 p=.100	-.2526 29 p=.186
Distraction	.0574 29 p=.767	1.000 30 p=.	.1265 30 p=.505	-.1265 30 p=.505	.2467 30 p=.189	.1754 30 p=.254	-.1547 30 p=.414	-.3403 30 p=.066	-.2000 30 p=.289	.1762 30 p=.352	.0976 30 p=.608
Social withdrawal	.0759 29 p=.696	.1265 30 p=.505	1.000 30 p=.	-.1000 30 p=.599	.2786 30 p=.136	.3467 30 p=.061	-.1956 30 p=.300	.0978 30 p=.607	.1265 30 p=.505	-.1115 30 p=.558	-.1543 30 p=.416
Cognitive restructuring	.1935 29 p=.315	-.1265 30 p=.505	-.1000 30 p=.599	1.000 30 p=.	.2229 30 p=.236	-.1387 30 p=.465	-.0978 30 p=.607	.3424 30 p=.064	.02530 30 p=.177	.1115 30 p=.558	.0000 30 p=1.000
Self criticism	.0725 29 p=.709	.2467 30 p=.189	.2786 30 p=.136	.2229 30 p=.236	1.000 30 p=.	.2473 30 p=.188	.0927 30 p=.626	.2562 30 p=.172	.0352 30 p=.853	.1180 30 p=.535	-.3612 30 p=.050
Blame	-.0148 29 p=.939	.1754 30 p=.254	.3467 30 p=.061	-.1387 30 p=.465	.2473 30 p=.188	1.000 30 p=.	.0950 30 p=<.618	-.1085 30 p=.568	-.0877 30 p=.645	-.0155 30 p=.935	-.2568 30 p=.171
Problem solving	.1009 29 p=.603	-.0622 29 p=.749	.0253 29 p=.897	.3111 29 p=.100	-.2526 29 p=.186	-.0148 29 p=.939	1.000 30 p=.	.2823 30 p=.131	.0309 30 p=.871	.3980 30 p=.029	-.4076 30 p=.025
Emotional regulation	-.0622 29 p=.749	.0253 29 p=.897	.3111 29 p=.100	-.2526 29 p=.186	-.0148 29 p=.939	1.000 30 p=.	.2823 30 p=.131	1.000 30 p=.	.0309 30 p=.871	-.0927 30 p=.0453	.0453 30 p=.812
Wishful thinking	.0253 29 p=.897	.3111 29 p=.100	-.2526 29 p=.186	-.0148 29 p=.939	1.000 30 p=.	.2823 30 p=.131	.0309 30 p=.871	.0309 30 p=.871	1.000 30 p=.	-.0352 30 p=.853	-.0976 30 p=.078
Social support	.3111 29 p=.100	-.2526 29 p=.186	-.0148 29 p=.939	1.000 30 p=.	.2229 30 p=.236	-.1387 30 p=.465	.0927 30 p=.626	.2562 30 p=.172	.0352 30 p=.853	1.000 30 p=.	-.3268 30 p=.078
Resignation	-.2526 29 p=.186	.0976 30 p=.608	-.1543 30 p=.416	.0000 30 p=1.000	-.3612 30 p=.050	-.2568 30 p=.171	-.4076 30 p=.025	.0453 30 p=.812	-.0976 30 p=.608	-.3268 30 p=.078	1.000 30 p=.

Table 24: Zero order correlational matrix for the 10 individual coping strategies and externalising behaviour problems (Pearson's r coefficient/ Cases/ 2-tailed significance)

	External'g	Distraction	Social withdrawal	Cognitive restruct'g	Self criticism	Blame	Problem solving	Emotional regulation	Wishful thinking	Social support	Resignat' n
Externalisin g	1.000 29 p= .	.0076 29 p= .969	.2329 29 p= .224	.1834 29 p= .341	-.0155 29 p= .936	-.1408 29 p= .466	-.0068 29 p= .972	.0121 29 p= .950	.0308 29 p= .874	.1383 29 p= .474	-.1834 29 p= .341
Distraction	.0076 29 p= .969	1.000 30 p= .	.1265 30 p= .505	-.1265 30 p= .505	.2467 30 p= .189	.1754 30 p= .254	-.1547 30 p= .414	-.3403 30 p= .066	-.2000 30 p= .289	.1762 30 p= .352	.0976 30 p= .608
Social withdrawal	.2329 29 p= .224	.1265 30 p= .505	1.000 30 p= .	-.1000 30 p= .599	.2786 30 p= .136	.3467 30 p= .061	-.1956 30 p= .300	.0978 30 p= .607	.1265 30 p= .505	-.1115 30 p= .558	-.1543 30 p= .416
Cognitive restructuring	.1834 29 p= .341	-.1265 30 p= .505	-.1000 30 p= .599	1.000 30 p= .	.2229 30 p= .236	-.1387 30 p= .465	-.0978 30 p= .607	.3424 30 p= .064	.02530 30 p= .177	.1115 30 p= .558	.0000 30 p= 1.000
Self criticism	-.0155 29 p= .936	.2467 30 p= .189	.2786 30 p= .136	-.1000 30 p= .599	1.000 30 p= .	.2473 30 p= .188	.0927 30 p= .618	.2562 30 p= .568	.0352 30 p= .645	.1180 30 p= .935	-.3612 30 p= .171
Blame	.1408 29 p= .466	.1754 30 p= .254	.3467 30 p= .061	-.1387 30 p= .465	.2473 30 p= .188	1.000 30 p= .	.0950 30 p= .626	-.1085 30 p= .172	-.0877 30 p= .853	-.0155 30 p= .535	-.2568 30 p= .050
Problem solving	-.0068 29 p= .972	-.0076 30 p= .969	-.1956 30 p= .414	-.0978 30 p= .607	.0927 30 p= .618	.0950 30 p= .568	1.000 30 p= .	.2823 30 p= .131	.0309 30 p= .871	.3980 30 p= .029	-.4076 30 p= .025
Emotional regulation	.0121 29 p= .950	-.3403 30 p= .066	.0978 30 p= .606	1.000 30 p= .	.0309 30 p= .871	.0309 30 p= .871	.2823 30 p= .131	1.000 30 p= .	.0309 30 p= .871	-.0927 30 p= .626	.0453 30 p= .812
Wishful thinking	.0308 29 p= .874	-.2000 30 p= .289	.1000 30 p= .505	.2530 30 p= .177	.0352 30 p= .853	-.0877 30 p= .645	.0309 30 p= .871	.0309 30 p= .871	1.000 30 p= .	-.0352 30 p= .853	-.0976 30 p= .608
Social support	.1383 29 p= .474	.1762 30 p= .352	-.1115 30 p= .558	.1115 30 p= .558	.1180 30 p= .535	-.0155 30 p= .935	.3980 30 p= .029	-.0927 30 p= .0453	-.0352 30 p= .853	1.000 30 p= .	-.3268 30 p= .078
Resignation	-.1834 29 p= .341	.0976 30 p= .608	-.1543 30 p= .416	.0000 30 p= 1.000	-.3612 30 p= .050	-.2568 30 p= .171	-.4076 30 p= .025	.0453 30 p= .812	-.0976 30 p= .608	-.3268 30 p= .078	1.000 30 p= .

4 Discussion

4.1 The aims of the present research

This research was primarily concerned with identifying the specific patterns of strategies and beliefs which might be associated with improved functioning of children with Juvenile Chronic Arthritis. The aim was to better understand the factors associated with successful adaptation, in order to intervene effectively with children who are having difficulties coping with Juvenile Chronic Arthritis.

This was attempted by surveying the self-reports of children diagnosed with Juvenile Chronic Arthritis in a community sample. Measures of pain intensity, anxiety, self esteem, depression and parental ratings of behavioural problems were used as criterion (dependent) variables. The children's reported coping strategies and health locus of control beliefs were entered as predictor (independent) variables.

4.2 Summary of main findings

4.2.1 Normative data

The use of standardised assessment tools allowed the comparison of this research group with published normative data on healthy children. What is striking from this comparison, is that the sample of children with Juvenile Chronic Arthritis reported in this study, compares very favourably with healthy norms.

With the exception of the 7 year old boys, all of the age groups fell within or below acceptable levels of total anxiety. Self esteem scores for the entire sample were either within or above the average range and depression scores were below the cut-off score indicating depression, with the exception of 7 year olds. The anomalous findings for 7 year olds should be treated with caution as no actual norms for this age group are provided by the Self-Perception Profile for children and the Childhood Depression

Inventory. In terms of behavioural problems, scores were generally below the borderline range for symptomatic problems, with a slightly elevated parental report of internalising problems. This is expected, given the tendency for the nature of the illness and parental underestimation of ability to artificially increase these scores.

The above evidence suggests that the general feeling that the majority of children cope effectively with chronic paediatric conditions, is confirmed (for example Midence, 1994; Eiser, 1990b). The subjects surveyed report their general health similarly, and in some cases better off, than peer group normative samples. However, this 'healthy' group is perhaps too biased towards children coping effectively and may include a disproportionate number of children in remission. Research with greater numbers may resolve this problem and uncover more significant contributions of coping and health locus of control.

4.2.2 Coping strategies

The present research found that the global coping styles postulated by Spirito and colleagues (Spirito, Stark, & Williams, 1988; Spirito, Stark, & Tyc, 1989; Stark, Spirito, & Tyc, 1991) of positive/ approach and active/ avoidance did not appear to explain the variance in outcome measures. However, this is not entirely surprising given the fact that a cursory look at the internal relationships did not show that the items making up the scales of positive/ approach and negative/ avoidance were significantly correlated. In this way some doubt exists over the validity of these scales within this study. Future investigations with much higher participant numbers, are necessary to further clarify these issues as the low number of subjects reported in this study may not allow these properties to emerge.

Despite this problem, there were some interesting findings from the analysis of individual coping strategies. Perhaps the most striking finding in this study is the consistent amount of variance explained by the strategy of social withdrawal. The

strategy is associated with higher current and worst pain report, elevated anxiety and depression levels, as well as poorer self esteem.

In addition to social withdrawal, there were other strategies which were associated with outcome. Firstly, resignation was associated with higher current pain. Secondly, increased use of problem solving was associated with higher levels of worst pain. Thirdly, distraction was correlated with lower anxiety scores and lower total depression. Finally, increased use of social support was associated with elevated self report scores of anxiety.

The present research did not find that any of the coping strategies explained the variance in reported of behavioural problems. It is worth noting that the behavioural problems are rated by parents and are thus provided by a separate source from the coping strategy reports. It is possible that the previously reported discrepancies between parent ratings and child self reports (for example Billings, Moos, Miller, & Gottlieb, 1987; Daltroy, Larson, Eaton, Partridge, Pless, Rogers, & Liang, 1992) have contributed to the lack of predictive power of coping on behavioural problems. However, this is not to say that parent reports are not valid. Additional research, again with increased numbers, should further investigate this relationship, particularly in light of the finding that children in this study were generally rated as within average limits for behavioural problems.

4.2.3 Health locus of control

The proportion of variance explained by health locus of control is non significant, with the exception of a trend towards significance of an increased belief in the control of powerful others and elevated anxiety scores. It is also of note that the unidimensional scores of children within this study were in general, the same as or slightly above those provided by age related normative data. It appears that global health locus of control for these children does not significantly deviate from those of healthy children.

There are three relevant points which may explain this unexpected result. Firstly, the lack of numbers of subjects surveyed in this study. This is described both above and below this section, and may contribute to the lack of significant contribution of health beliefs. Secondly, the scales themselves did not relate to each other particularly well. This may be related to the number of subjects or the fact that this study did not control for children's cognitive developmental level (this is discussed below). Finally, the lack of predictive value of health locus of control may be explained by the use of a global measure of health locus. Use of a specific arthritis health locus of control scale may address this problem (see Wallston, 1992).

4.3 Implications for clinical practice

The cross sectional, correlation design of this research does not allow a firm causative conclusion to be drawn from the results reported above. In addition, the expected effects which were hypothesised initially were not generally supported by the data collected by the study. However, there are a number of points which may help guide clinical interventions with children who are struggling to cope with Juvenile Chronic Arthritis.

Firstly, it appears that significantly poorer outcome is associated with those children who withdraw socially. Social withdrawal was associated with poorer outcomes on all children's self report measures. This may be a consequence of reduced ability to socialise, though it seems reasonable to assume that reducing social contact is likely to further impair effective psychosocial functioning. Thus, clinical interventions with children referred for maladjustment, might use behavioural strategies to enable these children to rebuild social contacts.

Secondly, distraction was a variable which appeared to explain some variance in terms of total anxiety and total depression. Specifically, as anxiety and depression became more severe, the use of distraction dropped. Causative implications are difficult to state firmly. However, it may be that when children are anxious or depressed they

concentrate or ruminate on their condition more. This may help maintain their symptoms. It is possible that direct instruction in distraction techniques may help children focus less on the disease process and may alleviate their higher levels of anxiety and depression.

Thirdly, the use of resignation is associated with higher reported current pain. The fact that children might 'give up' when pain is elevated is intuitively linked with social withdrawal. The fact that these strategies occur in conjunction suggests that children who report higher levels of current pain may be at risk of these withdrawal strategies. Thus, clinical intervention designed to mobilise their self motivation and ability to address their problems, may be beneficial.

Finally, discussion is warranted of the two results which were not predicted by this study. Specifically, the use of problem solving is associated with higher reports of worst pain, and utilising social support is associated with higher total anxiety levels. As discussed above it is difficult to attribute causal relations in correlational design. However, it is possible that as worst pain and anxiety increases, children are attempting to use problem solving and social support to cope with these factors. Future research using the efficacy scale of the KIDCOPE, which was left out of the analysis in this study, may help clarify this issue.

4.4 Methodological issues

4.4.1 Strengths of the present research

The current study has attempted to satisfy a number of the methodological criticisms which have been made of much previous research, in order to bring it into line with current opinion that research should emphasize factors which mediate successful adaptation to paediatric chronic illness.

Firstly, the purpose of this study was to assess a clinic sample of children as opposed to a biased sample of psychologically 'ill' children. Previous studies have often sampled from populations which have already been referred for psychological intervention (Pless, Cripps, Davies, & Wadsworth, 1989; Lemanek, Moore, Gresham, Williamson, & Kelley, 1986). By selecting children that fitted the age criteria with a diagnosis of Juvenile Chronic Arthritis from a general medical out patient clinic, it is felt that this particular objective has been achieved and that this sample should reflect the 'general' population of children with Juvenile Chronic Arthritis.

Secondly, and related to the first point, the study specifically approached a community sample of children and families. This aim was drawn from authors such as Bradford (1997) who believe that hospital in-patient populations have been over-researched in past studies. The vast majority of children with Juvenile Chronic Arthritis are managed at home, with the bulk of their care provided by parents. Hospital populations are likely to be in acute crisis and are unlikely to represent the general population as a whole. It is also has been shown that children in hospital have different primary concerns than those who are at home(Stark, Spirito & Tyc, 1991).

Thirdly, the research has attempted to reflect the recent change in theory and research into chronic illness, specifically, the increasing recognition that, despite being potentially at risk for maladjustment, many children successfully adapt to the rigours of having a chronic illness (Eiser, 1990b, 1993; Bradford, 1997; Midence, 1994). The emphasis within the study has been on several factors which might mediate adaptation, those of coping and health locus of control. These concepts were selected from the theoretical basis of the risk and resistance model (Varni & Wallander, 1988; Wallander & Varni, 1992; 1995; 1998), as well as from previous research which had emphasised the importance of children's coping efforts (Olson, Johansen, Powers, Pope, & Klein, 1993; Ellerton, Ritchie, & Caty, 1994) and health beliefs (LaMontagne, 1984; 1987; 1993), as well as their interrelation (Rao, Subbakrishna, & Prabhu, 1990; Petrosky & Birkimer, 1991).

Finally, the study has surveyed children's self-reports and perceptions of pain and disability. There is an increasing belief that too often parents, teachers and professionals are asked to venture opinions on the child's adaptation to illness (Ennett, DeVellis, Earp, Kredich, Warren, & Wilhelm, 1991). This view has been adopted by the author along with the recognition that children can reliably give accurate indications of their disease experience and general health status (Wallander, Varni, Babani, Banis, & Wilcox, 1988; Billings, Moos, Miller, & Gottlieb, 1987; Varni, Thomson, & Hanson, 1987).

4.4.2 Methodological criticisms of the present study

Whilst the study has a number of strengths in terms of its design, there are a number of areas in which criticism and suggestions for future research could be made. It is important to note that this research has been undertaken within strict time frames for its completion. Thus some of the methodological problems discussed herein may be related to this issue. For example the time constraints did not allow for a longitudinal design, which has been advocated in much of the criticism of previous research. This and other related issues are discussed in detail below.

4.4.3 Correlational design

The first methodological problem to be considered is that of correlational design. Whilst this design method is useful in examining potential relationships between variables, it does not directly assess the nature of theoretical questions (Wertleib, Weigel, & Feldstein, 1987; Olson, Johansen, Powers, Pope, & Klein, 1993). Correlational designs can highlight associations between factors, but do not pinpoint the direction of the relationship (Ennett, DeVellis, Earp, Kredich, Warren, Wilhelm, 1991). Research in this field should focus on determining causal relationships, for example whether cognitive behavioural interventions to encourage use of active coping strategies or internal locus of control beliefs effect changes on outcome variables (Beckham, Keefe, Caldwell, & Roodman, 1991).

4.4.4 Cross-sectional sampling

Secondly, this study relies on a cross sectional sampling of children's perceptions. Juvenile chronic arthritis has an unpredictable, intermittent course which varies between disease manifestation and remission, creating problems for cross sectional designs (Eiser, 1990b). Many authors have called for longitudinal designs to fully assess the nature and stability of coping and health beliefs over time (Parkes, 1984; Wertleib, Weigel, & Feldstein, 1987; Compas, 1987; Ennett et al, 1991).

In addition, this type of design allows long term longitudinal follow up (Quirk & Young, 1990). As previously attested to, this study precluded carrying longitudinal sampling due to practical constraints. However, the bulk of the literature now calls for the use of these designs to adequately assess the long term adaptation to chronic childhood conditions.

4.4.5 Measures of disease severity

An additional concern is the lack of use of multiple measures of disease severity. Whilst the study did survey the important variable of current pain in children (Hagglund, Schopp, Alberts, Cassidy, & Frank, 1995), no other indication of disease severity was used within the study. Beckham and colleagues (Beckham, Keefe, Caldwell, & Roodman, 1991) call for the use of multiple measures of severity, such as joint counts and sedimentation rates. Future research should aim to incorporate these factors.

4.4.6 Single site sampling

Fourthly, the present study sampled from a single Out-Patient Rheumatology Clinic population. Methodologically, this practice should be avoided as it the sample will reflect the biases of one particular clinic philosophy, approaches to care, and its population (Olson at al, 1993; Eiser, 1990b). For example, the Consultants at the Rheumatology Clinic at the Royal Hospital for Sick Children, are keen to utilise psychological input and thus many of these children are seen for cognitive-behavioural treatment. However, this philosophy might not reflect the practices of other hospital clinics.

Lavigne and Faier-Routman (1992) have termed the use of single clinic designs as 'samples of convenience', which contribute to biases in terms of referral patterns, region, social economic status, race, and specific medical practices. This creates problems for generalising research findings to the population of children with chronic illness as a whole.

Inadequate sample selection has been a constant criticism of research into paediatric chronic illnesses (Quirk & Young, 1990) and owes much to the relatively small numbers of children available to researchers within any given locale. Eiser (1990b) has advocated the use of population versus clinic based studies.

In relation to the criticism of number of subjects, detailed below, single centre research studies do tend to generate small sample sizes, especially given the number of variables typically assessed in studies (Quirk & Young, 1990; Ennett et al, 1991). In this way many authors have called for multi-centre studies to be carried out to address this problem (Lavigne & Faier-Routman, 1992; Quirk & Young, 1990).

4.4.7 Sample size

Further criticism can be levelled at the small sample size reported in this paper. Whilst time constraints limited the ability to survey a wider proportion of the families suitable for the study (15% of those approached were unable to participate within the time frame), 30 is still seen as a limited number (Quirk & Young, 1990). It is likely that important subtle differences will have been masked by this lack of subjects. For example Olson and colleagues (Olson et al, 1993), reported that 100 to 200 subjects may in fact be too small to detect subtle differences. Ross and colleagues concluded that the 56 families sampled in their study was not enough (Ross, Lavigne, Hayford, Berry, Sinacore, & Pachman, 1993), whilst sample sizes of between 23 and 57 have been deemed too small to divide children into diagnostic categories for adequate analysis of disease specific variables (Jaworski, 1993).

The repercussions from small sample sizes extend to the requirements for multiple regression analysis. As previously discussed the numbers in the present study are limited in terms of the number of variables assessed. Additional issues of multicollinearity are also raised as the number of variables entered within analysis increases to the limits set by the number of subjects. Ideally, the number of subjects should have been substantially higher to adequately assess all the variables entered.

4.4.8 Control group

A sixth consideration is that this study did not employ the use of a control group. Whilst some authors do advocate the use of within group designs (Moise, 1986; Hurtig and White, 1986), this view is still widely debated (Lemanek, Moore, Gresham, Williamson, & Kelley, 1986; Olson et al, 1993). In a review of research into the pain-related and psychosocial aspects contributing to Juvenile Chronic Arthritis, Jaworski (1993) concluded that future research should make more use of control groups and debate exists over whether these groups should consist of healthy children or children suffering from other paediatric conditions.

Other authors, noting the difficulties in adequate matching of healthy children and families to those coping with a chronic illness, suggest that the use of siblings as a control group might be a possible solution (Quirk & Young, 1990; Lavigne & Faier-Routman, 1992). This might go a long way to match children for most demographic and environmental characteristics and allow the investigation of the specific parameters associated with adaptation to the disease process itself.

4.4.9 Demographic variables

A further point for discussion, related to the second point discussed above, is the lack of inclusion of demographic variables within the analysis, termed by Quirk & Young (1990) 'important intervening variables', such as gender, age, developmental state of adaptation, and ordinal position within the family. These authors identify the failure to assess interrelations between physical disease aspects and psychosocial functioning, as a feature of much research in this area. Much of this problem within this study is contributed to by the small sample size. However, demographic variables have been implicated in most models of childhood chronic illness (for example, Varni & Wallander, 1988; Wallander and Varni, 1992; 1995; 1998).

In a study on the psychological factors affecting reported pain in Juvenile Chronic Arthritis, Ross and colleagues found that the combination of psychological variables *with* disease parameters accounted for over half the variance in prospective monthly pain report (Ross, et al 1993). The authors also advocated the importance of specific diagnoses of Juvenile Chronic Arthritis, as well as other factors. For example, Polyarthritis may be associated with higher pain report and family harmony also appeared to play an important role in children's pain report. Future research should address these disease specific characteristics.

4.4.10 Items included in data collection

In terms of the data collected within this study, there are a number of points that could be raised. Quirk & Young (1990), in their review of research and methodology in this area, felt that global scales, such as those used primarily in this analysis, are not as good as specific subscales.

In addition, there has been much debate about the usefulness of the concept of locus of control (Wallston, 1992). Initial changes to the concept saw the move to a specific health related scale with multidimensional constructs. However, Wallston (1992) points out that it is imperative to include some measure of the *value* of health to the individual, if one is properly applying the social learning theory concepts which underlie health locus of control.

Furthermore, there has been a call to employ more disease specific measures of health locus of control as the general concept has often failed to explain significant proportions of variance (for a review see Wallston, 1990). It is possible that the failure to find significant relationships between health locus of control and other variables in this study, might be rectified by the use of a control scale designed specifically for Juvenile Chronic Arthritis (Neuhauser, Amsterdam, Hines, & Steward, 1978).

4.4.11 Reliance on children's self-report

One of the proposed strengths of the current research was the use of children's self report. This was based on the findings that mothers in particular tend to underestimate children's abilities (Quirk & Young, 1990) and often over-report psychological difficulties (Ennett et al, 1991). However, potential criticism might be levelled at the reliance on children's self-reports. Researchers have indicated that, whilst it is desirable to survey children's views themselves, studies should also focus beyond

these views to gather information from additional sources (Band, 1990; Mabe, Treiber, & Riley, 1991).

Jaworski (1993) suggests that the reliability and validity of observational methods of data collection require further interest and investigation as there are inherent problems in relying on a single method of data collection. In addition, other reviews have advocated the use of structured interviews and symptom reports in studies of children with chronic physical illness (Eiser, 1990b; Lavigne & Faier-Routman, 1992).

4.4.12 Children's cognitive developmental level

Finally, the present research did not include a measure of children's developmental ability which has been recently advocated as an important factor to be accounted for in research (Jaworski, 1993, Quirk & Young, 1990). Cognitive level has been implicated in the variability of disease education success, misconceptions about illness and treatment in children, as well as the experience of pain and discomfort (Berry, Hayford, Ross, Pachman, Lavigne, 1993).

As research into children's coping abilities becomes more popular, the role of cognitive development is being seen as a central tenet in models of coping (Perrin & Gerrity, 1984; Band 1990). Berry and colleagues (Berry et al, 1993) emphasize that research should not merely assume that accounting for age differences is adequate, but should assess developmental level specifically.

Neuhauser and colleagues concluded that, when considering locus of control factors in children, it is important to take into account cognitive developmental level (Neuhauser et al, 1978). They found that developmental level affects the amount of control children perceive. In addition, cognitive level interacts with the level of abstractness of the concept. For example, "illness" was a more abstract concept than a visible injury. The importance of cognitive developmental level has led to the suggestion that it may be necessary to design alternative forms of measures for

different cognitive levels (Compas, 1987) as well as adjust expectations for education and treatment responsibility (Band, 1990; Berry et al, 1993).

4.5 Implications for future research

The purpose of this discussion has been to highlight the critical points emerging from this research. Whilst some indications of possible effects have been highlighted, the hypotheses proposed by the author have been largely unsubstantiated. In the light of the methodological points discussed above, the implications for continuing research studies into the adaptation of children and their families to Juvenile Chronic Arthritis are clear.

Future research should be designed to include longitudinal, multi-centre studies of children diagnosed with arthritis, living in the community. This method will address criticisms of cross-sectional designs, small sample sizes and the associated lack of attention paid to arthritis type. In addition, longitudinal studies will facilitate assessment of the stability of beliefs and coping over time, and during periods of disease activity and remission. The possibility of using siblings as controls is also worthy of investigation.

This author postulates that the concepts of locus of control and coping will remain important aspects of future research. The use of an arthritis-specific health locus of control scale for children should be investigated, as this may uncover the role of disease-specific health beliefs. The lack of numbers used in this study may have masked the effects of cognitive coping strategies and this may be addressed by larger scale sampling. However, future researchers might be advised to examine the properties of the *efficacy scale* of the KIDCOPE, which was neglected in this study. Clinical experience from this study showed that, whilst children indicated they used emotion focused/ avoidant strategies, they often rated them as having no effect on their reported pain. These factors may lead to important effects if they are included within future research using this measure.

Finally, there are several other factors which should be included in future research. Firstly, the cognitive developmental level of children should be assessed and used within analysis, in preference to age. Secondly, other measures of disease severity, such as joint counts should be included. Thirdly, studies should continue to use children's self-report *in addition to* parents' ratings and those from physicians. Finally, analysis should aim to examine the possible variable effects of the different forms of Juvenile Chronic Arthritis.

4.6 Concluding comment

This study was primarily concerned with the contributions that coping style and health locus of control make to outcome in children with Juvenile Chronic Arthritis. Whilst the results of this research are mixed, there are a number of important factors which may have contributed to the lack of significant findings.

However, it appears that increased use of social withdrawal and resignation are associated with poorer outcome, whilst use of distraction techniques drop with increasing anxiety and depression. These findings might go some way towards guiding clinical interventions, as well as providing some directions for the focus of future research.

The author firmly believes that further research is justified within this field, as there is still much to be learnt about how children and families adjust to the condition of Juvenile Chronic Arthritis. It is proposed that future research should take heed of the methodological issues discussed herein. If so, the understanding of children's and family's responses to Juvenile Chronic Arthritis and our ability to plan effective, relevant clinical interventions for children who are referred for adjustment difficulties, should be advanced significantly, and thus paediatric psychologists will be better able to target the specific needs of those children and families using appropriate interventions.

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APPENDIX I

RESEARCH INFORMATION SHEET

This study is looking at how children with Juvenile Chronic Arthritis cope with their joint pain. The purpose is to examine which types of coping strategies are associated with lower reported pain and better reported quality of life. In addition, we hope to find out how children's sense of control over their health affects their ability to cope with their pain.

Our aim is to identify the strategies and beliefs that help children cope. We will then use this information to help guide us when we help children who are having difficulty coping with their illness and their pain. We are therefore asking children with Juvenile Chronic Arthritis and their families to take part in the study.

If you are interested in taking part you will attend an appointment with the researcher lasting approximately 20 minutes. At this appointment you will be given more information about the study and the researcher will answer any questions you may have. You will then be given time to think about your decision to take part. If you are still unsure at this time, another appointment can be arranged for you. If you consent to participate in the study, the researcher will first ask you some general questions about your child's health. You, and your child, will then be given some questionnaires to complete.

The questionnaires ask your child to indicate where they felt pain or discomfort that day and how bad it was. Other questionnaires ask your child to say how they coped with the discomfort and also how they felt about themselves that day.

Your participation is entirely voluntary and should you decide not to take part, this will not have any effect on your child's future care. If you decide to participate, you are free to stop at any time. We are required to tell your GP that you are taking part in the study and to let them know what it involves. We will do this by letter after your appointment.

Any information you give us will be treated as strictly confidential and nothing that could identify you or your child will be published in any form. Questionnaires will be kept only for the period of this research (approximately 7 months) and then destroyed. Only members of the research team will have access to them. Once the research is completed, we can let you know how to obtain the results if you wish.

If you have any questions, you can contact a member of the research team or our independent adviser. We really appreciate your participation in this study, as it will give us a better understanding of how children handle their difficulties, so we can provide a more helpful service to them.

For more information please contact:-

Ion Wyness
Research Team Member
Child and Family Mental Health Services
Royal Hospital for Sick Children
3 Rillbank Terrace
Edinburgh, EH9 1LL
Tel: 0131-536-0534

or for independent advice contact:-

Mrs Brenda Renz
Head of Psychology
Child and Family Mental Health Services
Royal Hospital for Sick Children
3 Rillbank Terrace
Edinburgh, EH9 1LL
Tel: 0131-536-0534

THANK YOU FOR YOUR HELP

APPENDIX I

LOTHIAN RESEARCH ETHICS COMMITTEE

STANDARD CONSENT FORM

TITLE OF THE PROPOSED RESEARCH:

The effect of coping strategies and health locus of control, on perception of pain and perceived health in children with Juvenile Chronic Arthritis.

NAME OF INVESTIGATOR:

Mr Ion James Wyness

ADDRESS:

Child and Family Mental Health Service
Royal Hospital for Sick Children
3 Rillbank Terrace
EDINBURGH EH9 1LL

TELEPHONE:

0131-536-0534

FURTHER INFORMATION IS AVAILABLE FROM: (A person who is not involved in the study)

Mrs Brenda Renz
Head of Psychology
Child and Family Mental Health Service
Royal Hospital for Sick Children
3 Rillbank Terrace
EDINBURGH EH9 1LL

LIST ANY DRUGS TO BE GIVEN IN THE STUDY EXPLAINING THEIR ACTION:

None

LIST ANY PROCEDURES REQUIRED IN ADDITION TO THE STANDARD PROCEDURES:

None

- I agree to participate/to the patient/subject participating* in this study.

APPENDIX I

- I have read this consent form and Patient/Subject Information Sheet and had the opportunity to ask questions about them.
- I agree for notice to be sent to my/the patient's/subject's* General Practitioner about my/their* participation in this study.
- I agree to the provision of any clinically significant information to my/the patient's/subject's General Practitioner.
- I understand that I am/the patient/subject is* under no obligation to take part in this study and that a decision not to participate will not alter the treatment that I/the patient/subject* would normally receive.
- I understand that I have/the patient/subject has* the right to withdraw from this study at any stage and that to do so will not affect my/their* treatment.
- I understand that this is non-therapeutic research from which I/the patient/subject* cannot expect to derive any benefit.*

Signature of Patient/Subject/Parent or Guardian*

Name of Patient/Subject:

--

Signature of Investigator:

Date:

* Delete as appropriate

Four copies to be made

Top copy to be retained by Investigator

Second copy to be retained by patient/subject

Third copy to be sent to patient's/subject's General Practitioner

An additional copy to be filed in any relevant hospital case notes

CHILDHOOD ARTHRITIS QUESTIONNAIRE- CHILD FORM

THE FOLLOWING QUESTIONS ASK YOU ABOUT YOUR THOUGHTS AND FEELINGS TOWARDS HAVING ARTHRITIS. MOST OF THE QUESTIONS ASK YOU TO TICK A BOX OR CIRCLE A WORD.

THERE ARE NO RIGHT OR WRONG ANSWERS AND NONE OF THE ANSWERS YOU GIVE, WILL BE SHARED WITH ANYONE ELSE. REMEMBER TO ANSWER ALL THE QUESTIONS.

ANY QUESTIONS YOU HAVE CAN BE ANSWERED BY:-

ION WYNESS
CHILD AND FAMILY MENTAL HEALTH SERVICES
ROYAL HOSPITAL FOR SICK CHILDREN
3 RILLBANK TERRACE
EDINBURGH
EH9 1LL

TELEPHONE: 0131-536-0534

(Or contact Karen Shaw/Professor Julie Barlow: Telephone: 01203-838882)

Serial No.

Date

Name:-_____

Today's Date:-_____

Your Age:-_____ Sex (circle one) Girl Boy

What class are you in?:-_____

PAEDIATRIC PAIN QUESTIONNAIRE

Varni & Thomson (1985)

What words would you use to describe pain or hurt?

Put a mark on the line that best shows **how you feel now**. If you have no pain or hurt, you would put a mark at the end of the line by the happy face. If you have some pain or hurt, you would put a mark near the middle of the line. If you have a whole load of pain or hurt, you would put a mark by the sad face.



Not hurting
No discomfort
No pain



Hurting a whole lot
Very uncomfortable
Severe pain

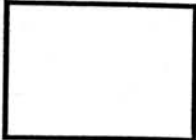
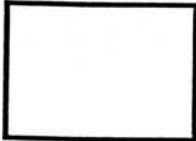
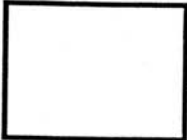
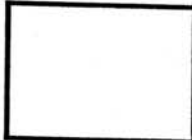
Put a mark on the line that best shows what was the **worst pain you had this week**. If you had no pain or hurt this week, you would put a mark at the end of the line by the happy face. If you had some pain or hurt, you would put a mark near the middle of the line. If the worst pain you had was a whole load of pain or hurt, you would put a mark by the sad face.



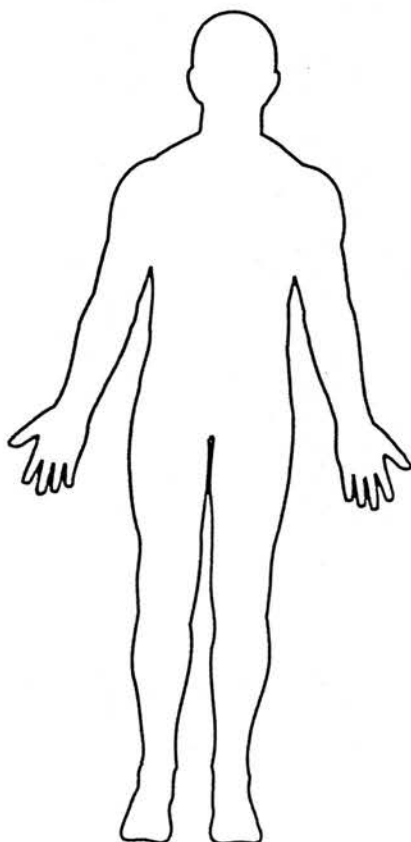
Not hurting
No discomfort
No pain



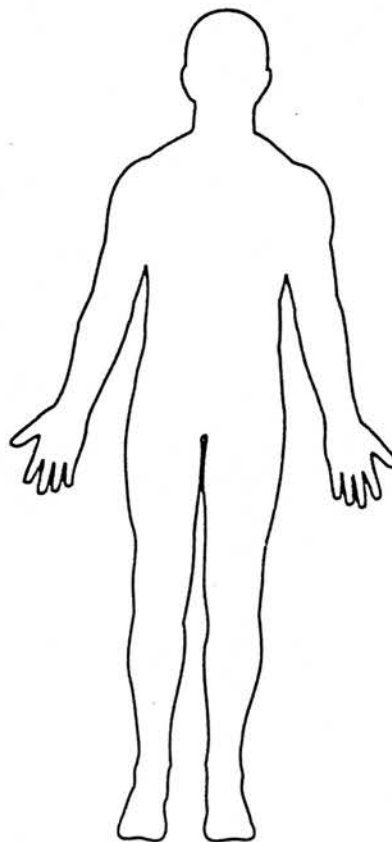
Hurting a whole lot
Very uncomfortable
Severe pain

No pain No hurt	Mild pain A little hurt	Moderate pain More hurt	Severe pain A lot of hurt
			

Pick the colours that mean **No hurt**, **A little hurt**, **More hurt**, and **A lot of hurt** to you and colour in the boxes. Now, using these colours, colour in the body to show how you feel. Where you have no hurt, use the **No hurt** colour to colour in your body. If you have hurt or pain, use the colour that tells how much hurt you have.



FRONT



BACK

KIDCOPE

Spirito, Stark, & Tye (1989)

We are trying to find out how children deal with the problems related to their arthritis. Think about the worst pain you had this week, which you described on the last page.

Read the questions below and circle the answer which most applies to how you felt:-

1.

Did this make you nervous?

Not at all

A little

Somewhat

Pretty much

Very much
2.

Did this make you sad?

Not at all

A little

Somewhat

Pretty much

Very much
3.

Did this make you angry or cross?

Not at all

A little

Somewhat

Pretty much

Very much

Now, please turn over this page and circle whether you used any of the following ways to help deal with the problem.

APPENDIX II

	Did you do this?		How much did it help?		
	Yes	No	Not at all	A little	A lot
1. I just tried to forget it.					
2. I did something like watch TV or played a game to forget it.					
3. I stayed by myself.					
4. I kept quiet about the problem.					
5. I tried to see the good side of things.					
6. I blamed myself for causing the problem.					
7. I blamed someone else for causing the problem.					
8. I tried to fix the problem by thinking of answers					
9. I tried to fix the problem by doing something or talking to someone.					
10 I shouted, screamed, or got angry.					
11 I tried to calm myself down.					
12 I wished the problem had never happened.					
13 I wished I could make things different.					
14 I tried to feel better by spending time with others like family, grown-ups, or friends.					
15 I didn't do anything because the problem couldn't be fixed.					

CHILDREN'S HEALTH LOCUS OF CONTROL SCALE

Parcel & Meyer (1978)

We would like to learn about different ways children look at their health. Here are some statements about health or illness (sickness). Some of them you will think are true and so you will circle YES. Some of them you will think are **not** true and so you will circle the NO. Even if it is very hard to decide, be sure to circle YES or NO for **every** statement. **Never** circle both YES and NO for one statement. There are not right or wrong answers. Be sure to answer the way **you** really feel and **not** the way other people might feel.

PRACTICE: Try the statement below.

a. Children can get sick

If you think this is true, circle _____ YES

If you think this is not true, circle _____ NO

b. Children never get sick

If you think this is true, circle _____ YES

If you think this is not true, circle _____ NO

Try one more statement for practice.

c. When I am not sick, I am healthy _____ YES NO

Now turn over this page and answer the questions in just the same way.

NOW DO THE REST OF THE STATEMENTS THE SAME WAY YOU PRACTICED.

- | | | |
|---------------------------------------------------------------------------|----------|----|
| 1. Good health comes from being healthy. | _____YES | NO |
| 2. I can do things to keep from being sick. | _____YES | NO |
| 3. Bad luck makes people sick. | _____YES | NO |
| 4. I can only do what the doctor tells me to. | _____YES | NO |
| 5. If I get sick, it is because getting sick just happens. | _____YES | NO |
| 6. People who never get sick are just plain lucky. | _____YES | NO |
| 7. My mother tells me how to keep from getting sick. | _____YES | NO |
| 8. Only a doctor or nurse keeps me from getting sick. | _____YES | NO |
| 9. When I am sick, I can do things to get better. | _____YES | NO |
| 10. If I get hurt it is because accidents just happen. | _____YES | NO |
| 11. I can do many things to fight illness. | _____YES | NO |
| 12. Only the dentist can take care of my teeth. | _____YES | NO |
| 13. Other people must tell me how to stay healthy. | _____YES | NO |
| 14. I always go to the nurse right away if I get hurt at school. | _____YES | NO |
| 15. The teacher must tell me how to keep from having accidents at school. | _____YES | NO |
| 16. I can make many choices about my health. | _____YES | NO |
| 17. Other people must tell me what to do when I feel sick. | _____YES | NO |
| 18. Whenever I feel sick I go to the school nurse right away. | _____YES | NO |
| 19. There are things I can do to have healthy teeth. | _____YES | NO |
| 20. I can do many things to prevent accidents. | _____YES | NO |

WHAT I THINK AND FEEL

Reynolds & Richmond (1985)

DIRECTIONS

Here are some sentences that tell how some people think and feel about themselves. Read each sentence carefully. Circle the word "Yes" if you think it is true about you. Circle the word "No" if you think it is **not** true about you. Answer every question even if some are hard to decide. Do not circle "Yes" and "No" for the same sentence.

There are no right or wrong answers. Only you can tell us how you think and feel about yourself. Remember, after you read each sentence, ask yourself "Is this true about me?". If it is, circle "Yes". If it is not, circle "No".

Now turn over this page and try the statements on the next page.

APPENDIX II

1.	I have trouble making up my mind.	YES	NO
2.	I get nervous when things do not go the right way for me.	YES	NO
3.	Others seem to do things easier than I can.	YES	NO
4.	I like everyone I know.	YES	NO
5.	Often I have trouble getting my breath.	YES	NO
6.	I worry a lot of the time.	YES	NO
7.	I am afraid of a lot of things.	YES	NO
8.	I am always kind.	YES	NO
9.	I get mad easily.	YES	NO
10.	I worry about what my parents will say to me.	YES	NO
11.	I feel that others do not like the way I do things.	YES	NO
12.	I always have good manners.	YES	NO
13.	It is hard for me to get to sleep at night.	YES	NO
14.	I worry about what other people think about me.	YES	NO
15.	I feel alone even when there are people with me.	YES	NO
16.	I am always good.	YES	NO
17.	Often I feel sick in my stomach.	YES	NO
18.	My feelings get hurt easily.	YES	NO
19.	My hands feel sweaty.	YES	NO
20.	I am always nice to everyone.	YES	NO
21.	I am tired a lot.	YES	NO
22.	I worry about what is going to happen.	YES	NO
23.	Other people are happier than I.	YES	NO
24.	I tell the truth every single time.	YES	NO
25.	I have bad dreams.	YES	NO
26.	My feelings get hurt easily when I am fussed at.	YES	NO
27.	I feel someone will tell me I do things the wrong way.	YES	NO
28.	I never get angry.	YES	NO
29.	I wake up scared some of the time.	YES	NO
30.	I worry when I go to bed at night.	YES	NO
31.	It is hard for me to keep my mind on my school work.	YES	NO
32.	I never say things that I shouldn't.	YES	NO
33.	I wiggle in my seat a lot.	YES	NO
34.	I am nervous.	YES	NO
35.	A lot of people are against me.	YES	NO
36.	I never lie.	YES	NO
37.	I often worry about something bad happening to me.	YES	NO

WHAT I AM LIKE

Really True for me	Sort of True for me			Sort of True for me	Really True for me
<input type="checkbox"/>	<input type="checkbox"/>	Some kids would rather play outside in their spare time	BUT	Other kids would rather watch T.V.	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel that they are very good at their school work	BUT	Other kids worry about whether they can do their school work	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids find it hard to make friends	BUT	Other kids find it's pretty easy to make friends	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids do very well at all kinds of sports	BUT	Other kids don't feel that they are good when it comes to sports	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are happy with the way they look	BUT	Other kids are not happy with the way they look	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids often do not like the way they behave	BUT	Other kids usually like the way they behave	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are often unhappy with themselves	BUT	Other kids are pretty pleased with themselves	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel like they are just as clever as other kids	BUT	Other kids aren't so sure and wonder if they are as clever	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids have a lot of friends	BUT	Other kids don't have many friends	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish they could be a lot better at sports	BUT	Other kids feel they are good enough at sports	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are happy with their height or weight	BUT	Other kids wish their height and weight or different	<input type="checkbox"/>

APPENDIX II

Really True for me	Sort of True for me			Sort of True for me	Really True for me
<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually do the right thing	BUT	Other kids often don't do the right thing	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids don't like the way they are leading their life	BUT	Other kids do like the way they are leading their life	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are pretty slow in finishing their school work	BUT	Other kids can do their school work quickly	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids would like to have a lot more friends	BUT	Other kids have as many friends as they want	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids think they could well at any new sport	BUT	Other kids are afraid they might not do well at new sports	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish their body was different	BUT	Other kids like their body the way it is	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually behave the way they know they're supposed to	BUT	Other kids often don't behave the way they're supposed to	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are happy with themselves as a person	BUT	Other kids are often not happy with themselves	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids often forget what they learn	BUT	Other kids can remember things easily	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are always doing things with a lot of kids	BUT	Other kids usually do things by themselves	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel that they are better at sports than their friends	BUT	Other kids don't feel they can play as well	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids wished they looked different	BUT	Other kids like the way they look	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually get into trouble because of things they do	BUT	Other kids usually don't do things that get them in trouble	<input type="checkbox"/>

APPENDIX II

Really True for me	Sort of True for me			Sort of True for me	Really True for me
<input type="checkbox"/>	<input type="checkbox"/>	Some kids like the kind of person they are	BUT	Other kids often wish they were someone else	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids do very well at their class work	BUT	Other kids don't do very well at their class work	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish that more people their age liked them	BUT	Other kids feel that most people their age do like them	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	In games and sports some kids usually watch instead of play	BUT	Other kids usually play rather than just watch	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish something about their face or hair looked different	BUT	Other kids like their face and hair the way they are	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids do things they know they shouldn't do	BUT	Other kids hardly ever do things they know they shouldn't do	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are very happy being the way they are	BUT	Other kids wish they were different	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids have trouble working out the answers in school	BUT	Other kids almost always can work out the answers	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are popular with others their age	BUT	Other kids are not very popular	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids don't do well at new outdoor games	BUT	Other kids are good at new games right away	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids think that they are good looking	BUT	Other kids think that they are not very good looking	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids behave themselves very well	BUT	Other kids often find it hard to behave themselves	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	Some kids are not very happy with the way they do a lot of things	BUT	Other kids think the way they do things is fine	<input type="checkbox"/>

CDI

Kovacs (1981)

Children sometimes have different feelings and ideas. This form lists the feelings and ideas in groups. From each group pick *one* sentence that describes you best for the past two weeks. After you pick a sentence from one group, go on to the next group, and right to the end.

There is no right or wrong answer. Just pick the sentence that describes the way *you* have been feeling recently.

PUT A MARK LIKE THIS



IN THE



NEXT TO YOUR ANSWER.

Here is an example of how the form works. Try it. Put a mark next to the sentence that describes you best.

EXAMPLE

- ☐ I READ BOOKS ALL THE TIME
- ☐ I READ BOOKS ONCE IN A WHILE
- ☐ I NEVER READ BOOKS

NOW TURN OVER THIS PAGE AND TICK THE STATEMENTS ON THE FOLLOWING PAGES

REMEMBER PICK OUT THE SENTENCES THAT DESCRIBE HOW YOU HAVE BEEN FEELING AND THINKING RECENTLY.

APPENDIX II

- ☐ I AM SAD ONCE IN A WHILE
- ☐ I AM OFTEN SAD
- ☐ I AM SAD ALL THE TIME

- ☐ NOTHING WILL EVER WORK OUT FOR ME
- ☐ I AM NOT SURE IF THINGS WILL WORK OUT FOR ME
- ☐ THINGS WILL WORK OUT FOR ME

- ☐ I DO MOST THINGS WELL
- ☐ I DO MANY THINGS WRONG
- ☐ I DO EVERYTHING WRONG

- ☐ I ENJOY MANY THINGS
- ☐ I ENJOY SOME THINGS
- ☐ I DO NOT ENJOY ANYTHING

- ☐ I ALWAYS FEEL I AM A BAD PERSON
- ☐ I OFTEN FEEL I AM A BAD PERSON
- ☐ I RARELY FEEL I AM A BAD PERSON

- ☐ SOMETIMES, I THINK BAD THINGS WILL HAPPEN TO ME
- ☐ I WORRY THAT BAD THINGS WILL HAPPEN TO ME
- ☐ I AM SURE THAT TERRIBLE THINGS WILL HAPPEN TO ME

- ☐ I HATE MYSELF
- ☐ I DO NOT LIKE MYSELF
- ☐ I LIKE MYSELF

- ☐ EVERYTHING THAT GOES WRONG IS MY FAULT
- ☐ MANY THINGS THAT GO WRONG ARE MY FAULT
- ☐ THINGS THAT GO WRONG ARE USUALLY NOT MY FAULT

- ☐ I DO NOT THINK ABOUT HARMING OR KILLING MYSELF
- ☐ I THINK ABOUT HARMING OR KILLING MYSELF, BUT I WOULD NOT DO IT
- ☐ I WANT TO HARM OR KILL MYSELF

APPENDIX II

- ☐ I FEEL LIKE CRYING EVERY DAY
- ☐ I OFTEN FEEL LIKE CRYING
- ☐ I OCCASIONALLY FEEL LIKE CRYING

- ☐ THINGS BOTHER OR ANNOY ME ALL THE TIME
- ☐ THINGS OFTEN BOTHER OR ANNOY ME
- ☐ THINGS RARELY BOTHER OR ANNOY ME

- ☐ I LIKE BEING WITH OTHER PEOPLE
- ☐ SOMETIMES, I DO NOT LIKE BEING WITH OTHER PEOPLE
- ☐ I DO NOT LIKE BEING WITH OTHER PEOPLE MOST OF THE TIME

- ☐ I CANNOT MAKE UP MY MIND ABOUT THINGS ALL THE TIME
- ☐ I OFTEN CANNOT MAKE UP MY MIND ABOUT THINGS
- ☐ IT IS EASY TO MAKE UP MY MIND ABOUT THINGS

- ☐ MY LOOKS ARE FINE
- ☐ THERE ARE SOME FUNNY THINGS ABOUT MY LOOKS
- ☐ I LOOK UGLY

- ☐ I HAVE TO TRY HARD ALL THE TIME TO DO MY SCHOOL WORK
- ☐ OCCASIONALLY, I HAVE TO TRY HARD TO DO MY SCHOOL WORK
- ☐ DOING MY SCHOOL WORK IS NO PROBLEM

- ☐ EVERY NIGHT I HAVE TROUBLE SLEEPING
- ☐ OFTEN I HAVE TROUBLE SLEEPING
- ☐ I SLEEP WELL

- ☐ I AM TIRED ONCE IN A WHILE
- ☐ I AM OFTEN TIRED
- ☐ I AM TIRED ALL THE TIME

- ☐ MOST DAYS I DO NOT FEEL LIKE EATING
- ☐ OFTEN, I DO NOT FEEL LIKE EATING
- ☐ I EAT WELL

APPENDIX II

- ☐ I DO NOT WORRY ABOUT ACHES AND PAINS
- ☐ I OFTEN WORRY ABOUT ACHES AND PAINS
- ☐ I ALWAYS WORRY ABOUT ACHES AND PAINS

- ☐ I DO NOT FEEL LONELY
- ☐ I OFTEN FEEL LONELY
- ☐ I ALWAYS FEEL LONELY

- ☐ I NEVER HAVE FUN AT SCHOOL
- ☐ I OCCASIONALLY HAVE FUN AT SCHOOL
- ☐ I OFTEN HAVE FUN AT SCHOOL

- ☐ I HAVE PLENTY OF FRIENDS
- ☐ I HAVE SOME FRIENDS, BUT I WISH I HAD MORE
- ☐ I DO NOT HAVE ANY FRIENDS

- ☐ MY SCHOOL WORK IS FINE
- ☐ MY SCHOOL WORK IS NOT AS GOOD AS BEFORE
- ☐ I DO VERY BADLY IN SUBJECTS I USED TO BE GOOD AT

- ☐ I CAN NEVER BE AS GOOD AS OTHER CHILDREN
- ☐ I CAN BE AS GOOD AS OTHER CHILDREN IF I WANT TO BE
- ☐ I AM JUST AS GOOD AS OTHER CHILDREN

- ☐ NO ONE REALLY LOVES ME
- ☐ I AM NOT SURE IF ANYONE LOVES ME
- ☐ I AM SURE THAT SOMEONE LOVES ME

- ☐ I USUALLY DO WHAT I AM TOLD
- ☐ I OFTEN DO NOT DO WHAT I AM TOLD
- ☐ I NEVER DO WHAT I AM TOLD

- ☐ I GET ALONG WITH OTHER PEOPLE
- ☐ I OFTEN GET INTO FIGHTS
- ☐ I ALWAYS SEEM TO GET INTO FIGHTS

**THANK YOU VERY MUCH FOR
ANSWERING ALL THE
QUESTIONS**

**IF YOU WOULD LIKE TO WRITE ANY OF YOUR
OWN COMMENTS, PLEASE WRITE THEM HERE:-**

**THANK YOU ONCE AGAIN. YOUR ANSWERS
WILL LET US HELP CHILDREN WITH
ARTHRITIS MUCH BETTER IN THE FUTURE.**

CHILDHOOD BEHAVIOUR CHECK-LIST

Achenbach and Edelbrock (1983)

Below is a list of items that describe children. For each item that describes your child **now or in the last 6 months**, please circle **2** if the item is **very true or often true** of your child. If the item is **not true** of your child, please circle the **0**. Please answer all the questions as well as you can, even if they do not seem to apply to your child.

0= Not true (as far as you know)
 1= Somewhat or sometimes true
 2= Very true or often true

- | | | | |
|------------------------------------------------------------------------|---|---|---|
| 1. Acts too young for his/her age_____ | 0 | 1 | 2 |
| 2. Allergy_____ | 0 | 1 | 2 |
| (describe)_____ | | | |
| 3. Argues a lot_____ | 0 | 1 | 2 |
| 4. Asthma_____ | 0 | 1 | 2 |
| 5. Behaves like the opposite sex_____ | 0 | 1 | 2 |
| 6. Bowel movements outside the toilet_____ | 0 | 1 | 2 |
| 7. Bragging, boasting_____ | 0 | 1 | 2 |
| 8. Can't concentrate, can't pay attention for too long_____ | 0 | 1 | 2 |
| 9. Can't get his/her mind off certain obsessions_____ | 0 | 1 | 2 |
| (describe)_____ | | | |
| 10. Can't sit still, restless or hyperactive_____ | 0 | 1 | 2 |
| 11. Clings to adults or too dependent_____ | 0 | 1 | 2 |
| 12. Complains of loneliness_____ | 0 | 1 | 2 |
| 13. Confused or in a fog_____ | 0 | 1 | 2 |
| 14. Cries a lot_____ | 0 | 1 | 2 |
| 15. Cruel to animals_____ | 0 | 1 | 2 |
| 16. Cruelty, bullying or meanness to others_____ | 0 | 1 | 2 |
| 17. Day-dreams or gets lost in his/her thoughts_____ | 0 | 1 | 2 |
| 18. Deliberately harms him/herself or attempts suicide_____ | 0 | 1 | 2 |
| 19. Demands a lot of attention_____ | 0 | 1 | 2 |
| 20. Destroys his/her things_____ | 0 | 1 | 2 |
| 21. Destroys things belonging to his/her family or other children_____ | 0 | 1 | 2 |
| 22. Disobedient at home_____ | 0 | 1 | 2 |

APPENDIX II

23. Disobedient at school_____	0	1	2
24. Doesn't eat well at home_____	0	1	2
25. Doesn't get on well with other children_____	0	1	2
26. Doesn't seem to feel guilty after misbehaving_____	0	1	2
27. Easily jealous_____	0	1	2
28. Eats or drinks things that are not food_____	0	1	2
(describe)_____			
29. Fears certain animals, situations or places other than school_____	0	1	2
(describe)_____			
30. Fears going to school_____	0	1	2
31. Fears that he/she might think or do something bad_____	0	1	2
32. Feels that he/she has to be perfect_____	0	1	2
33. Feels or complains that nobody loves him/her_____	0	1	2
34. Feels others are out to get him/her_____	0	1	2
35. Feels worthless or inferior_____	0	1	2
36. Gets hurt a lot, accident-prone_____	0	1	2
37. Gets in many fights_____	0	1	2
38. Gets teased a lot_____	0	1	2
39. Hangs around with children who get into trouble_____	0	1	2
40. Hears things that aren't there_____	0	1	2
(describe)_____			
41. Impulsive or acts without thinking_____	0	1	2
42. Likes to be alone_____	0	1	2
43. Lying or cheating_____	0	1	2
44. Bites fingernails_____	0	1	2
45. Nervous, highly-strung or tense_____	0	1	2
46. Nervous movements or twitching_____	0	1	2
47. Nightmares_____	0	1	2
48. Not liked by other children_____	0	1	2
49. Constipated, doesn't move bowels_____	0	1	2
50. Too tearful or anxious_____	0	1	2
51. Feels dizzy_____	0	1	2
52. Feels too guilty_____	0	1	2
53. Overeating_____	0	1	2
54. Overtired_____	0	1	2
55. Overweight_____	0	1	2

APPENDIX II

56. Physical problems without medical cause			
(a) Aches or pains_____	0	1	2
(b) Headaches_____	0	1	2
(c) Nausea, feels sick_____	0	1	2
(d) Problems with eyes_____	0	1	2
(describe)_____			
(e) Rashes or other skin complaints_____	0	1	2
(f) Stomach-aches or cramps_____	0	1	2
(g) Vomiting or throwing up_____	0	1	2
(h) Other_____	0	1	2
(describe)_____			
57. Physically attacks other people_____	0	1	2
58. Picks nose, skin or other parts of body_____	0	1	2
(describe)_____			
59. Plays with his/her own sex parts in public_____	0	1	2
60. Plays with his/her own sex parts too much_____	0	1	2
61. Poor school work_____	0	1	2
62. Poorly co-ordinated or clumsy_____	0	1	2
63. Prefers playing with older children_____	0	1	2
64. Prefers playing with younger children_____	0	1	2
65. Refuses to talk_____	0	1	2
66. Repeats certain acts over and over; compulsions_____	0	1	2
(describe)_____			
67. Runs away from home_____	0	1	2
68. Screams a lot_____	0	1	2
69. Secretive, keeps things to him/herself_____	0	1	2
70. Sees things that aren't there_____	0	1	2
(describe)_____			
71. Self-conscious or easily embarrassed_____	0	1	2
72. Sets fires_____	0	1	2
73. Sexual problems_____	0	1	2
(describe)_____			
74. Showing off or clowning_____	0	1	2
75. Shy or timid_____	0	1	2
76. Sleeps less than most children_____	0	1	2
77. Sleeps more than most children during the day or night_____	0	1	2
78. Smears or plays with bowel movements_____	0	1	2
79. Speech problem_____	0	1	2
(describe)_____			

APPENDIX II

80. Stares blankly_____	0	1	2
81. Steals at home_____	0	1	2
82. Steals outside the home_____	0	1	2
83. Stores up things he/she doesn't need_____	0	1	2
(describe)_____			
84. Stange behaviour_____	0	1	2
(describe)_____			
85. Strange ideas_____	0	1	2
(describe)_____			
86. Stubborn, sullen or irritable_____	0	1	2
87. Sudden changes in mood or feelings_____	0	1	2
88. Sulks a lot_____	0	1	2
89. Suspicious_____	0	1	2
90. Swearing or obscene language_____	0	1	2
91. Talks about killing him/herself_____	0	1	2
92. Talks or walks in his/her sleep_____	0	1	2
93. Talks too much_____	0	1	2
94. Teases a lot_____	0	1	2
95. Temper tantrums or a hot temper_____	0	1	2
96. Thinks about sex too much_____	0	1	2
97. Threatens people_____	0	1	2
98. Thumb sucking_____	0	1	2
99. Too concerned with neatness or cleanliness_____	0	1	2
100. Trouble sleeping_____	0	1	2
101. Truancy, skips school_____	0	1	2
102. Underactive, slow moving or lacks energy_____	0	1	2
103. Unhappy, sad or depressed_____	0	1	2
104. Unusually loud_____	0	1	2
105. Uses alcohol, drugs or sniffs glue_____	0	1	2
106. Vandalism_____	0	1	2
107. Wets him/herself during the day_____	0	1	2
108. Wets the bed_____	0	1	2
109. Whining_____	0	1	2
110. Wishes to be opposite sex_____	0	1	2
111. Withdrawn, doesn't get involved with others_____	0	1	2
112. Worrying_____	0	1	2
113. Please write any problem your child has that was not listed above:-			
_____	0	1	2